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The Effects of Insomnia on Older Adults' Quality of Life and Daily Functioning

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The Effects of Insomnia on Older Adults' Quality of Life and Daily Functioning

by

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Dedication

To Lucy, Jessica, and Freddie

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Abstract

The Effects of Insomnia on Older Adults' Quality of Life and Daily Functioning

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Older adults who move from their own homes to a retirement community, or to assisted living, and in many cases, again to long-term care or a nursing home, pass through a trajectory of increasing dependence reflected in their living situation. Disordered sleep or insomnia is frequently a key factor when older adults move down this trajectory of dependence, either as a primary cause or as a symptom of worsening physical or cognitive function, but how and why this happens has not been explored. Insomnia in older adults has been linked to increased incidence of falls, depression and anxiety, suicide attempts, cognitive impairment, institutionalization and overall mortality, but traditional sleep assessment instruments, designed for the general adult population, fail to capture many of the experiences and precipitating factors that are unique to older adults. This qualitative descriptive study elicited self-report and open narratives from 18 older adults at two different points along the trajectory of dependence about their own sleep behaviors, their knowledge of good sleep hygiene, and their thoughts and beliefs about the relationships between sleep, daily functioning and quality of life. The interviews were supplemented with five self-report instruments and a sleep diary. Conventional content analysis of the

participants' narratives revealed the overriding theme of Insomnia Is Exhausting, which exemplifies the physical and emotional strain this chronic condition creates, and four categories: A Bad Night, Self-Management, Stoicism and Consequences. By employing qualitative methods that captured a more holistic and nuanced experience of insomnia, this study demonstrated the negative effects that insomnia has on older adults' quality of life and daily functioning. This study has implications for nursing education and practice, research and policy.

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Chapter 1: Introduction

Irene is an 86-year-old retired teacher living in a one-bedroom apartment in the independent living section of a large, well-regarded continuing care retirement complex in Austin, TX. She moved to the community three years ago, a year after her husband, Derrick, died. She and Derrick had lived in their family home in Austin for more than 50 years and raised their children, David and Linda, there. Linda now lives in Atlanta, but David, and his wife, Julie, and their two children live in Austin and visit Irene regularly. Irene describes her health as "pretty good for my age". She has arthritis, and takes medication for hypertension and depression, which was prescribed for her after her husband's death. When she first moved to the community she still drove during the daytime, but she has not used her car for the last two years.

Since she moved to the complex Irene has had trouble sleeping. She says she goes to bed at 11pm and frequently lies awake until after 1am. "I just lie there thinking and I can't turn my brain off," she says. On the nights when she does go to sleep quickly, she often finds herself awake from 3am-5am and is still exhausted the next day. Her daughter-in-law has told her not to lie in bed if she can't sleep, but to get up, so she goes to the living room and does jigsaw puzzles on her iPad until she feels sleepy again.

Irene has not mentioned her sleep problems to her doctor, but she admits that she is frequently too tired to go to her exercise class in the mornings and has pretty much stopped going to the church she has attended for more than 20 years because she is "just worn out" after a bad night's sleep. She had been a regular at the complex's movie night with a group of friends, but in recent months decided she could only go to the afternoon shows, because the 8pm showing frequently left her too agitated to be able to sleep. After one of her bad nights, Irene frequently naps for about an hour in the afternoon in her armchair in front of the TV but finds that she is not refreshed afterwards.

Irene reports that she occasionally feels she is forgetting things but says she relies on the calendar on her iPad for reminders. However, in the last few months she has turned up two days early for her hair appointment at the complex's salon and then did not come at all on her regular day. The complex's receptionist, Tanya, reported that Irene sat on the bench outside the main entrance with her overnight bag for over an hour one day waiting to be picked up by her son, but when Tanya finally got a hold of David, he said they had not had any arrangement or appointment. When David came to see her the next day Irene was embarrassed to admit that she had lost her iPad in her apartment and so was unable use the reminder app and calendar. David was a little surprised to find the iPad in a stack of books on the floor of the bathroom, but he told his mother to phone him if she lost it again, explaining that he would activate the Find My iPhone app for her from his own computer. This happened three times in the next month. But the third time, David received the call at 215am from James, the night receptionist, who said Irene had been walking in the halls because she couldn't sleep and had misplaced the iPad again. After reassuring Irene that David would activate the app, James offered to walk Irene back to her room, sensing that she was a little confused. Irene burst into tears and said she had also lost her keys and didn't know the way back to her apartment.

David and Julie are now concerned that Irene is not safe in her apartment and requested a meeting with the complex manager to discuss the possibility of moving Irene to the assisted living side of the complex.

BACKGROUND AND SIGNIFICANCE

Insomnia is a significant health problem for older adults that has far-reaching negative effects on older adults' daily functioning and quality of life. The Institute of Medicine (IOM) declared sleep disorders and sleep deprivation "an unmet public health problem" for the whole population and noted that for older adults the problem is too often overlooked (Institute of Medicine, 2006). For older adults, like Irene in the previous case study, chronic insomnia is too often dismissed as an unpleasant consequence of aging, like presbyopia or fragile skin. But in

reality, insomnia is both a problem in itself and at the same time can be a symptom of other, potentially serious mental or physical health issues. Multiple research studies have found that insomnia in older adults is linked to increased incidence of falls (Krishnan & Hawranik, 2008a; Martin & Ancoli-Israel, 2008), depression and anxiety (Ford & Kamerow, 1989; Potvin, Lorrain, Belleville, Grenier, & Préville, 2014), suicide attempts (Bernert, Turvey, Conwell, & Joiner, 2014), cognitive impairment (Almondes, Costa, Malloy-Diniz, & Diniz, 2016; Bliwise, 1993; Ju et al., 2013), institutionalization (Pollak & Perlick, 1991), and overall mortality (Dew et al., 2003; Pollak, Perlick, Linsner, Wenston, & Hsieh, 1990). Yet many health care providers consider insomnia an inevitable effect of aging (Institute of Medicine, 2006; Pollak et al., 1990; Reid et al., 2006), a situation that led Benca to declare the condition, "under-recognized, underdiagnosed, and undertreated" (Benca, 2005, p. 332). The purpose of this chapter is to introduce the importance of exploring older adults' views about insomnia and its effects on quality of life and daily functioning. This chapter presents the background and significance of the problem; the purpose of this study; the conceptual models used; the specific research questions to be answered; the definitions of major terms; and the assumptions and limitations of this study.

Insomnia in Older Adults

Insomnia is a serious health problem and one of the most prevalent of all mental health disorders. Insomnia is characterized by a subjective perception of difficulty initiating or maintaining sleep, and can involve difficulty getting to sleep at the beginning of the night, difficulty staying asleep through the night, or premature awakening in the morning with an inability to fall back asleep, associated with significant distress or impairment of daytime functioning (American Academy of Sleep Medicine, 2014; American Psychiatric Association, 2013; Voyer, Verreault, Mengue, & Morin, 2006). Epidemiological reports of insomnia vary somewhat depending on the diagnostic criteria used and population assessed, but it is estimated that 10-15% of the healthy adult population has chronic insomnia (sleep difficulties lasting more than a month), while an additional 25-35% has occasional or transient insomnia (Benca, 2005;

Foley et al., 1995; Lichstein, Taylor, McCrae, & Petrov, 2016; Ohayon, 2002). Among older adults (age 65+), however, the prevalence rates are much higher, ranging from 25-57% for people living in the community to 65% of people living in institutions (Foley et al., 1995; Fung et al., 2012; Martin & Ancoli-Israel, 2008; Voyer et al., 2006). The reasons for this increased prevalence of insomnia among older adults are complex and are examined in greater detail in Chapter 2. In the past, researchers tried to determine whether this increase in insomnia (and corresponding decrease in sleep quality and duration) in older adults could be due to circadian rhythm changes that come with aging, or to external, and potentially modifiable factors, such as stress, medication regimes, pain, nocturia, or poor environment. However, the most recent guidelines from the National Sleep Foundation stated that healthy older adults and younger adults require comparable amounts of sleep, but that multiple health, social and environmental risk factors make achieving that needed sleep much more difficult (Hirshkowitz et al., 2015; Petrov, Vander Wal, & Lichstein, 2014).

A Trajectory of Dependence

Many of these risk factors for insomnia materialize as life changes, such as retirement, bereavement, the onset of chronic illness or disability, or changes of living situation, that many older adults and their families perceive as losses or signs of increasing dependency. Moreover, it is common for an older adult to experience many or all of these life changes in different combinations or in fairly rapid succession over a short period of time. In the case study, Irene experienced the death of her husband, the loss of her family home and a move into an institutional living situation, all within one year. Older adults who move from their own homes to a retirement community, or to assisted living, and in many cases, again to long-term care or a nursing home, pass through a trajectory of increasing dependence reflected in their living situation (see Figure 1). On this trajectory, each stage, or change in living situation, represents a reduction in personal competence and independence, a loss of control of personal routines and environment, and the imposition of greater social and physical restrictions.

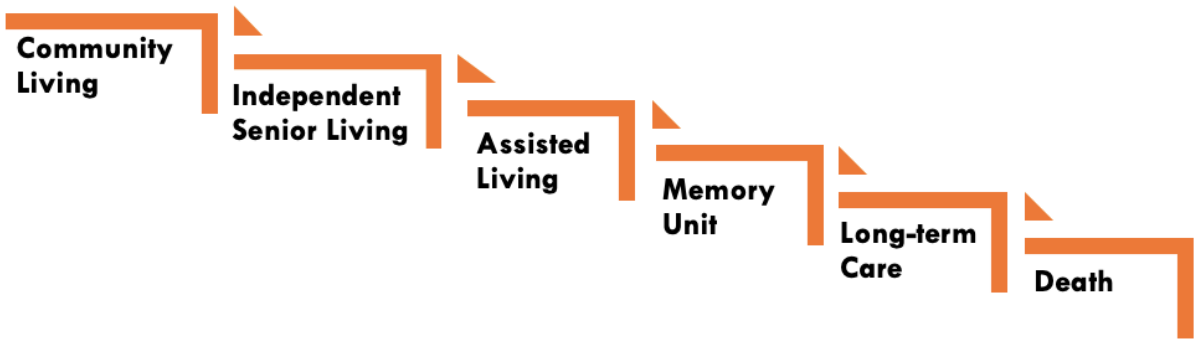


Figure 1. A Trajectory of Dependence

This full trajectory of dependence is not experienced by all older adults. In 2016, the most recent year for which data are available, there were 49.2 million older adults in the United States, representing 15.2% or about one in every seven Americans (Administration on Aging, 2018). The Administration on Aging reported that a relatively small number (1.5 million) and percentage (3.1%) of the population aged 65+ live in institutional settings, but noted that the percentage increases dramatically with age, ranging from 1% for persons ages 65-74 to 3% for persons ages 75-84 and 9% for persons age 85 and over (Administration on Aging, 2018). Clearly, most people live independently until their death, and those who do move to some kind of institutional living situation do not necessarily experience all stages of the trajectory. In addition, the timescale can vary tremendously, because some people descend the trajectory slowly, perhaps over a period of 20 years or more, while others may move through all of the stages in a month.

Many senior communities or institutions that provide safe housing and care for older adults offer different living situations and levels of care that correspond to the stages of this trajectory of dependence. This study focused on the views of residents of two stages of the trajectory: independent senior living and assisted living. Independent living within a retirement community offers older adults who require minimal to no assistance a supervised house or apartment where they can pursue their own activities without having to look after their own home or yard (Bemis,

2017; Lawton, 1990). Vendors of independent senior living communities cite reduced responsibilities, increased socialization and easy access to care as some of the main advantages of moving to an independent living community (American Seniors Housing Association, 2017). Assisted living, in contrast, is designed for older adults who require some assistance with activities of daily living (ADLs) and/or medication management. Assisted living complexes tend to consist of smaller one-bedroom or studio apartments with the option of communal dining facilities. The National Center for Assisted Living reports that more than 800,000 older adults live in assisted living communities in the US, and that the most common types of assistance needed are with bathing and walking (National Center For Assisted Living, 2019). In advising people about levels of care required, the American Seniors Housing Association suggests that if any of the following criteria are met by an older adult, assisted living should be considered:

- The adult has experienced at least one fall, with or without injury.
- Meal preparation is becoming more difficult.
- Family members have noticed signs of hunger or that nutritional needs aren't being met.
- It's getting harder for them to safely maneuver around the house.
- More help is needed getting dressed, bathing, managing medication or with other activities of daily living.
- Family members are worried about isolation and/or their safety (American Seniors Housing Association, 2017)

How, and when, a resident moves from one stage of the trajectory to the next (for example, from an independent living apartment to assisted living) and the criteria or qualifications for such a move, vary according to the physical environment, staffing levels, management policies of the community or institution and -- one hopes -- the wishes of the resident involved. The decision to move to assisted living or independent senior living accommodation can be a stressful one, and disordered sleep or insomnia is frequently a key factor in such a move down the trajectory, either as a primary cause or as a symptom of worsening physical or cognitive function. Efforts to evaluate

the role of sleep loss in older adults' physical and cognitive decline can be complicated by the fact that moving into more restricted living arrangements in itself worsens sleep (Ancoli-Israel, 2004; Martin, Fiorentino, Jouldjian, Josephson, & Alessi, 2010; Orestis, 2013). Older adults experiencing this transition, or step down the trajectory, have to adjust to a new, physical environment, new care staff and routines, and very often, increased noise, dependency, loss of privacy and autonomy and worsening health. People in the midst of major life changes can expect acute, or short-term insomnia, but for older adults, the problem is frequently more serious, because these changes are frequently permanent, and associated with loss of autonomy and increased dependency (Bickerstaff, Grasser, & McCabe, 2003; Lawton, 1990; Martin et al., 2010).

Measuring a Subjective Condition

Geriatric insomnia has been researched sporadically over the last 30 years or so from a variety of perspectives. Studies have focused on gathering epidemiological data (Ancoli-Israel, 2004; Foley et al., 1995; Van Someren, 2000), describing links between disturbed sleep and chronic illness (Foley, Ancoli-Israel, Britz, & Walsh, 2004; Manocchia, Keller, & Ware, 2001; Sampaio, Sewo Sampaio, Yamada, Tsuboyama, & Arai, 2014), and there have been a number of intervention studies aimed at improving older adults' sleep quality through therapies such as yoga, tai chi, mindfulness, or exercise (Black, O'Reillby, Olmstead, Breen, & Irwin, 2015; Chan et al., 2016; Lai et al., 2017; Sivakumar et al., 2013). From the perspective of different stages of the trajectory of dependence, several research groups have examined sleep disturbance among residents of long-term care facilities (Martin & Ancoli-Israel, 2008; Pollak & Perlick, 1991; Voyer et al., 2006), or among residents of assisted living facilities (Fung et al., 2012; Martin et al., 2010; Rao et al., 2005). But all of these studies relied almost exclusively on quantitative analysis using one or two sleep instruments: the Pittsburgh Sleep Quality Index (PSQI) or the Insomnia Severity Index (ISI) (Bastien, Vallières, & Morin, 2001; Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). Both instruments are self-report sleep questionnaires that ask participants to check predetermined responses or to complete a Likert-style "always, sometimes, never" profile.

However, there are many factors specifically relating to older adults' life experiences that are not captured by these instruments, such as bereavement or institutionalization or change of living environment (Carney et al., 2012; Landry, Best, & Liu-Ambrose, 2015). It may be that researchers considered self-report survey data to be sufficient indication of participants' views, but Likert-style questionnaires or pre-determined responses do not allow respondents to explain their own experiences or to supply history, context, and insights about insomnia. This extra information is essential to understand how insomnia affects older adults whose lives are often transitioning as family needs, health status, and environments change.

This problem was explicitly brought to light during the development of the Consensus Sleep Diary. The expert panel of insomnia researchers that developed the Consensus Sleep Diary, in an effort to standardize insomnia research methodologies, found that while the participants in their trial focus groups agreed with the quantitative dimensions of the new prototype, they felt the format "limited their ability to adequately convey the entirety of their sleep experience, and they advocated for additional means to describe these experiences" (Carney et al., 2012, p. 301). The authors recommended that in clinical and research settings these more qualitative aspects of sleep and wakefulness be captured by other more efficient methods, such as specific patient-reported outcomes or interviews (Carney et al., 2012). Clearly there is need for more nuanced, experiential reporting of sleep. Furthermore, the instruments have changed little since the late 1980s, and so do not reflect societal changes in older adults' living situations or personal habits in the age of smart phones, iPads and other culture-changing technology.

Another factor in insomnia diagnosis and treatment is the highly subjective nature of insomnia itself; it is very much in the eye of the beholder. Sleep laboratories use polysomnography (PSG) to provide objective measures of people's sleep activity, including brain activity, heart rhythm, eye movement and skeletal muscle activation, and yet there is some evidence that people's own perceptions of their sleep are more significant for their health status than objective measurements with actigraphy or PSG (Haimov, Breznitz, & Shiloh, 2005; Landry et al., 2015; Magee, Caputi, & Iverson, 2011). Some people sleep three to four hours a night but do not consider

that a problem, and others seek help from sleep specialists because they actually sleep six or even seven hours a night but feel continually fatigued and unable to function. The inherently subjective nature of an insomnia diagnosis is reflected in both the latest diagnostic criteria from the American Psychiatric Association (APA), which requires that the sleep disturbance cause significant distress or impairment in social, occupational, educational, academic, behavioral, or other important areas of functioning (American Psychiatric Association, 2013), and in the widespread use of self-report instruments, as opposed to objective measures such as actigraphy or PSG. However, scores on these self-report instruments do not fully reflect the complex psychological and physiological components of insomnia for older adults.

With such strong subjective components to insomnia, and the emphasis in gerontology and geriatric care on maintaining quality of life for older adults, it is surprising, therefore, that there has not been greater use of qualitative methodology to explore these concepts**.** Sleep is an inherently subjective experience that would benefit from research through the holistic, fluid perspectives of qualitative methodology, and yet has been most frequently studied quantitatively. This lack of qualitative study is especially concerning when there is so much evidence that, for older adults, insomnia is frequently triggered or exacerbated by factors like bereavement, recent relocation, anxiety, institutionalization, polypharmacy or comorbidities that are not explicitly addressed in the instruments and surveys commonly used in insomnia research. Quality of life considerations also change as people age and face possible disability or chronic illness, and the prospect of becoming more dependent (Bowling & Stenner, 2011; Lawton, 1983, 1991; Levasseur et al., 2009; Sullivan & Asselin, 2013). Insomnia affects older adults' daily functioning and health, and their voices and perceptions need to be included in research aimed at fully understanding the complex interplay between insomnia and quality of life in order to develop possible solutions for this growing population.

In summary, this study addressed gaps in the literature by eliciting the views of groups of older adults in two different and progressively more restrictive living situations -- independent living and assisted living (two distinct stages on the trajectory of dependence) – to record their

perceptions of the effect that insomnia has on their quality of life and daily functioning. This study is significant because:

- It begins to address an overlooked and potentially modifiable disorder (insomnia) that has heavy costs to physical and mental health, that can lead to institutionalization and mortality in older adults.
- The qualitative interviews elicited the thoughts and beliefs of older adults, taking a small step to close the large deficit of qualitative research concerning insomnia and provided insights about experiences and coping strategies employed by this population to cope with the effects of insomnia.
- The results of this study provided insights that can contribute to the design or delivery of insomnia interventions for older adults across dependency levels.

PURPOSE

The purpose of this qualitative descriptive study was to elicit self-report and open narratives from older adults at two different points along the trajectory of dependence about their own sleep behaviors, their knowledge of good sleep hygiene, and their thoughts and beliefs about the relationships between sleep, daily functioning and quality of life in order to understand how insomnia affects this population.

MODEL

Given the complex nature of this study, two conceptual frameworks informed the analysis of this work: The Ecological Theory of Aging and the Spielman 3P Model for Insomnia. These two conceptual models share a behaviorist perspective and reflect complementary aspects of the purpose of this dissertation. The models provide a lens for exploring how older adults' sleep changes in different living environments as they become more dependent; how insomnia affects quality of life in these living environments; and what personal adaptations and coping strategies older adults may employ in each situation.

M. Powell Lawton developed the Ecological Theory of Aging in the 1970s, as part of his decades-long research into the effect of living environments on older adults' ability to cope with aging, increasing dependence, and its effects on their quality of life. Lawton was a behavioral psychologist and an early advocate for living spaces designed for frail elderly people, and particularly people with Alzheimer's disease (Lawton, 1990; Lawton & Nahemow, 1973; Saxon, 2001). The Ecological Theory of Aging describes the interdependence of person and environment as a set of personal competencies set against "environmental press" or the demands and contexts of a living environment (Lawton & Nahemow, 1973). Lawton and Nahemow's schematic of the theory (see Figure 2) shows a range from low competence and weak environmental press to high competence and strong environmental press, with a line representing an ideal adaptation level running roughly up the middle between the two.

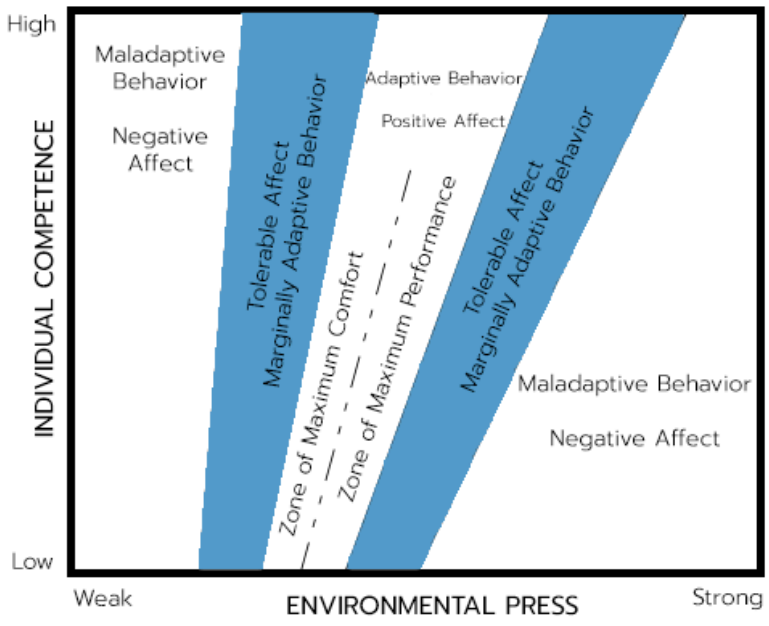


Figure 2. The Ecological Theory of Aging.

Adapted from Lawton, M., & Nahemow, L. (1973). Ecology and the aging process. In C. Eisdorfer & M. Lawton (Eds.), *Psychology of adult development and aging.* Washington, D.C: American Psychological Association

On either side of the adaptation level are two zones: zone of maximum comfort and the zone of maximum performance potential, where, according to Lawton and Nahemow, established competence and environmental adaptation result in good quality of life (Lawton & Nahemow, 1973). For example, the increased restriction of an assisted living studio apartment compared to an independent apartment or house may come as a relief to a frail or fearful person by reducing his or her environmental press. Or it may be a source of increased stress to someone functioning at a higher competence level who resents the loss of independence. A memory unit resident with high personal competence, who is accustomed to more varied social interaction than many units normally provide, may become angry, depressed or uncooperative because of the low level of environmental press. According to the Ecological Theory of Aging, the goal should be to keep older adults within the zones of maximum comfort and performance level, where their individual competences are balanced against the demands of the environment and they experience good quality of life.

Lawton revised and fine-tuned the Ecological Theory of Aging during the 1980s and early 1990s to reflect more accurately the agency of the older adult; clarifying the "transactional" nature of the interplay between person and environment, and emphasizing that the person is not a passive recipient of environmental change, but frequently creates changes and adaptations to suit his or her personal competencies (Lawton, 1985, 1991). Furthermore, this relationship between press and competency is a dynamic one, and people's interactions with their environments and their competencies change as they age (Lawton, 1982, 1983a, 1990). The Ecological Theory of Aging provided a model for evaluating the insomnia experiences of the participants in this study who are at varying levels on the trajectory of dependency and have different experiences of physical and/or cognitive decline, and different responses to levels of environmental press from their living situations.

The Spielman 3P model for insomnia allows Lawton and Nahemow's concepts of personal competence and environmental press to be applied to the experience of insomnia. Spielman and colleagues proposed that there are three types of factors that contribute to insomnia:

- Predisposing factors: Some psychological or biological characteristics increase vulnerability, or predisposition, to sleep difficulties (e.g., female gender, anxiety, hyperarousal).
- Precipitating factors: Life events and the medical, environmental or psychological factors can trigger acute insomnia (e.g., divorce, death of a significant other, illness, medication, familial or occupational stress).
- Perpetuating factors: Behaviors or beliefs can maintain or exacerbate insomnia after the precipitating event or trigger is resolved. Perpetuating behaviors are those that people adopt in order to cope with sleeplessness and include extending time spend in bed to try to sleep more and taking naps. Perpetuating beliefs and thoughts include fears of sleeplessness and excessive worries about daytime consequences of sleep (Spielman, Caruso, & Glovinsky, 1987).

This 3P Model (see Figure 3) demonstrates how insomnia occurs acutely, possibly after a precipitating event, and how predisposition and perpetuating behaviors can combine to make it into a chronic, self-perpetuating problem (Perlis, Shaw, Cano, & Espie, 2011; Spielman et al., 1987). The negative effects of perpetuating behaviors demonstrate why teaching about good sleep habits, or "sleep hygiene" is so important to improving sleep habits (Ancoli-Israel, 2004; Mastin, Bryson, & Corwyn, 2006; Spielman et al., 1987).

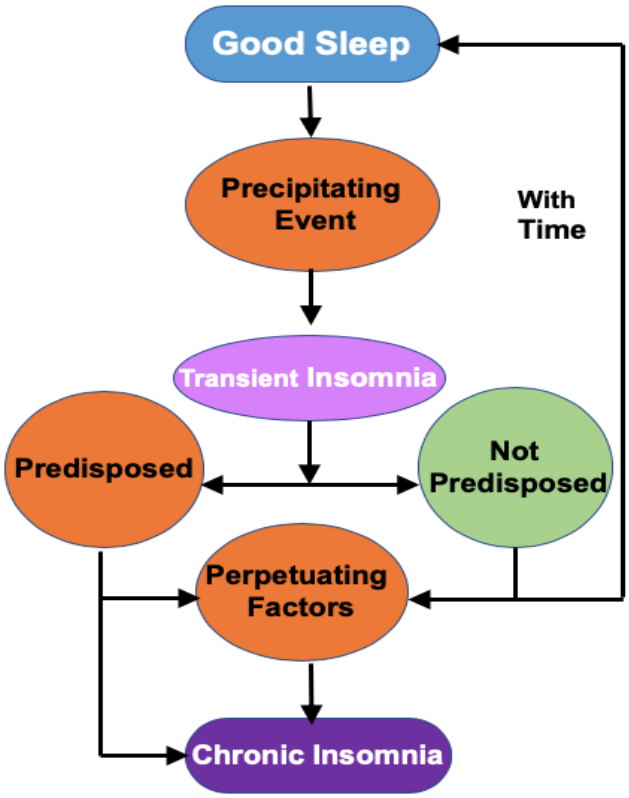


Figure 3. The 3P Model of Insomnia.

Adapted from Spielman, A., Nunes, J., & Glovinsky, P. (1996). Insomnia. *Neurologic Clinics*, *14*(3), 513–545.

The Spielman 3P Model was designed for the general adult population and many of the factors apply to anyone dealing with insomnia, while some characteristics and experiences – particularly in the precipitating factors -- are most frequently experienced by older adults. Because this study focuses on older adults, the factors determined to predispose older adults to insomnia included advanced age, female gender, and a history of anxiety. Factors that precipitated the onset of older adults' insomnia include death of a spouse, institutionalization, including moving to assisted living or a retirement community, and the onset or significant worsening of a chronic illness. Perpetuating factors included lack of understanding or attention to insomnia from

healthcare providers, dysfunctional beliefs and cognitions held by the older adult, and maladaptive habits. (These factors will be examined in greater detail in Chapter 2.) If these factors are examined through the lens of the Ecological Model, they can be considered as personal competencies or sources of environmental press that affect sleep quality. The predisposing factors relate to the individual, such as age or gender. The precipitating factors are frequently environmental presses, such as bereavement or institutionalization. The perpetuating factors include both environmental presses (lack of understanding by healthcare providers) and personal competences (dysfunctional cognitions).

RESEARCH QUESTIONS

The research questions this study addressed are:

- How do older adults living at two different points along the dependence trajectory describe the influence insomnia has on their quality of life?
- How do older adults' values, beliefs and behaviors about sleep contribute to their perceptions of the influence sleep has on their daily functioning?
- What are the sleep hygiene practices of older adults living at two different points along the dependence trajectory?

CONCEPTS AND DEFINITIONS

- Insomnia - Insomnia is characterized by a subjective perception of difficulty initiating or maintaining sleep, and can involve difficulty getting to sleep at the beginning of the night, difficulty staying asleep through the night, or premature awakening in the morning with an inability to fall back asleep, associated with significant distress or impairment of daytime functioning due to poor quality of sleep (American Psychiatric Association, 2013). For the purposes of this study insomnia will be measured or operationalized by the personal reports

of the participants and the data collected about their sleep with the Pittsburgh Sleep Quality Index, the Insomnia Severity Index, and the Consensus Sleep Diary.

- Quality of life – Quality of life is a concept that encompasses the individual's physical health, psycho-social well-being and function, independence, control over life, material circumstances, and external environment. It is a concept that is dependent on the perceptions of individuals and is likely to be mediated by cognitive factors (Bowling, 2005; Lawton, 1991). For the purposes of this study, quality of life will be measured or operationalized by the personal reports of the participants collected through qualitative interviews.
- Daily functioning refers to the knowledge, capacity and skills needed to care for oneself in the community environment (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963). For the purposes of this study daily functioning will be measured by the personal reports of the participants collected through qualitative interviews.
- Personal competencies are a diverse collection of abilities or innate aspects of functional capability, with biological, psychological and social components (Lawton, 1985, 1991; Lawton & Nahemow, 1973). For the purposes of this study, personal competencies are a component of quality of life, as expressed in the Ecological Theory of Aging, and will be measured by the personal reports of the participants collected through qualitative interviews.
- Environmental press consists of the demands that are placed on an individual by characteristics of the environment in which he or she lives (Lawton & Nahemow, 1973). For the purposes of this study, environmental press will be used as part of the Ecological Theory of Aging to help understand the experience of insomnia and its effect on daily function and quality of life and will be measured by the personal reports of the participants collected through qualitative interviews.
- Predisposing factors are psychological or biological characteristics that increase vulnerability, or predisposition, to insomnia (Perlis et al., 2011; Spielman et al., 1987). For

the purposes of this study, predisposing factors will be measured or operationalized by the personal reports of the participants collected through qualitative interviews.

- Precipitating factors are life events and/or medical, environmental or psychological stresses that can trigger acute insomnia (Perlis et al., 2011; Spielman et al., 1987). For the purposes of this study, precipitating factors will be measured or operationalized by the personal reports of the participants.
- Perpetuating factors are behaviors or beliefs that maintain or exacerbate insomnia after the precipitating event or trigger is resolved (Morin & Espie, 2004; Perlis et al., 2011; Spielman et al., 1987). For the purposes of this study, perpetuating factors will be measured or operationalized by the personal reports of the participants.
- Anxiety is characterized as an inability to control excessive worry or for more than six months, with symptoms including restlessness, irritability, fatigue, difficulty concentrating, and sleep disturbance (American Psychiatric Association, 2013). For the purposes of this study anxiety will be measured or operationalized by the personal reports of the participants and data collected about their anxiety through the Geriatric Anxiety Scale and the Dysfunctional Beliefs About Sleep Scale.
- Sleep habits are behaviors throughout the day and especially before bedtime that affect sleep quality and duration (Mastin et al., 2006; Stepanski & Wyatt, 2003). For the purposes of this study, sleep habits will be measured or operationalized by the personal reports of the participants, and by data collected on the Sleep Hygiene Index.
- Dysfunctional beliefs are faulty beliefs, excessive worries, and attentional biases that perpetuate and exacerbate insomnia (Carney et al., 2010; Morin, Stone, Trinkle, Mercer, & Remsberg, 1993). For the purposes of this study, dysfunctional beliefs will be measured or operationalized by the personal reports of the participants and by data collected on the Dysfunctional Beliefs About Sleep Scale.

ASSUMPTIONS AND LIMITATIONS

Assumptions

- Individuals perceive the environment around them.
- Individuals are self-reflective and consider consequences before taking action.
- Internal evaluation of abilities determines levels of self-efficacy in performing actions.
- Environmental factors influence actions of the individual.
- Individuals who have experienced insomnia will accurately and truthfully relay their thoughts and experiences.

Limitations

- All participants are residing at a single upscale retirement community and some of their perceptions and experiences may not be typical of older adults with lower socio-economic status.
- Including only English-speaking individuals does not allow for capture of the experience of non-English-speaking older adults.
- Individuals were asked to self-report their experiences with insomnia and they may have chosen not to report all their perceptions.

SUMMARY

This study addressed gaps in the literature by employing qualitative methods to elicit the views of older adults in two progressively more restrictive living situations -- independent living and assisted living (distinct stages on the trajectory of dependence)– to record their perceptions of the effect that insomnia has on their quality of life and daily functioning. Disordered sleep or insomnia is frequently a key factor when older adults move down the trajectory of dependence, either as a primary cause or as a symptom of worsening physical or cognitive function, but how and why this happens has not been explored. Sleep and quality of life are highly subjective experiences that would benefit from research through the holistic, fluid perspectives of qualitative

methodology, and yet have been most frequently studied quantitatively. This study is significant because:

- It begins to address an overlooked and potentially modifiable disorder (insomnia) that has heavy costs to physical and mental health, that can lead to institutionalization, and mortality in older adults.
- The qualitative interviews elicited the thoughts and beliefs of older adults, taking a small step to close the large gap in qualitative research around insomnia and provide insights about experiences and coping strategies utilized by this population to cope with the effects of insomnia.
- The results of this study provided insights that can contribute to the design of insomnia interventions for older adults across dependency levels.

Chapter 2: Review of Literature

INTRODUCTION

The purpose of this literature review was to examine existing published research about the factors that have been determined to contribute to insomnia in older adults, in order to gain an understanding of the possible causes of insomnia, why it becomes a chronic condition, and how it affects older adults' daily functioning and quality of life. This review begins with an explanation of changes to the definition of, and diagnostic criteria for, insomnia, and an overview of the concept of quality of life in gerontology. The main part of the review explores the factors that past researchers have determined lead to the development of insomnia, using the Spielman 3P model as a lens, and demonstrates how these factors function as sources of environmental press or personal competence under Lawton and Nahemow's Ecological Theory of Aging. The review concludes with a summary of the state of the science of geriatric insomnia and identifies critical gaps in this literature. The summary concludes with a discussion of how this dissertation attempted to address some of these specific empirical gaps.

Insomnia is researched in several disciplines, including nursing, medicine, psychiatry, and psychology, that frequently overlap in the multidisciplinary field of sleep science. Similarly, quality of life for older adults is a key concept in nursing, social gerontology, long-term care management, public health, social work, environmental psychology, and other disciplines working with the aging population, and the definitions and instrumentation used to evaluate this concept have varied by discipline and over time. Therefore, this literature review synthesized research that approaches these subjects from different disciplines and with different goals. It should also be noted that geriatric insomnia has received intermittent scholarly attention within sleep science for many years and as result, even the most recent studies regularly cite prevalence data and conclusions that date from the late 1990s or earlier. As a result, there was no chronological time limit on the studies included in this review.

Defining Insomnia

One notable change in the last 20 years has been revision of the definition and diagnosis of insomnia in the American Psychiatric Association's *Diagnostic and Statistical Manual* 5th edition (DSM-5), which was published in 2013. The DSM-5 lists the following criteria for a diagnosis of insomnia:

- The individual experiences dissatisfaction with sleep quantity or quality, with one or more of the following symptoms: difficulty initiating sleep, difficulty maintaining sleep, early-morning awakening.
- The sleep disturbance causes significant distress or impairment in social, occupational, educational, academic, behavioral, or other important areas of functioning.
- The sleep difficulty occurs at least three nights per week, is present for at least three months, and despite adequate opportunity for sleep.
- The insomnia does not co-occur with another sleep disorder.
- The insomnia is not explained by coexisting mental disorders or medical conditions (American Psychiatric Association, 2013).

The fifth edition removed DSM-4's distinction between primary and secondary insomnia, emphasized the comorbid nature of insomnia, particularly in people with psychiatric issues, and directed clinicians to treat both the insomnia *and* the other conditions (American Psychiatric Association, 2013; Lamberg, 2014; Lichstein et al., 2016). However, many of the most significant studies of the effect of insomnia on older adults pre-date this change, and some earlier works rely on the older DSM-3.

The American Academy of Sleep Medicine also refined its criteria for insomnia diagnosis in the third edition of the *International Classification of Sleep Disorders* (ICSD-3), which was published in 2014. Previous editions of the ICSD and the DSM had attempted to split insomnia into different types: primary vs secondary (that is, comorbid) or, in earlier editions, "organic" vs "nonorganic" insomnia. However, the panels guiding the new edition noted that serious reservations existed with "the nature of the associations and the direction of causality" in cases of

comorbid insomnia (Sateia, 2014, p. 1388). As a result, the ICSD third edition combines all chronic insomnia into one diagnosis, with the following criteria:

- A report of sleep initiation or maintenance problems
- Adequate opportunity and circumstances to sleep
- Daytime consequences (Sateia, 2014)

The majority of the studies in this literature review relied on one of these two sources for insomnia diagnosis criteria. However, studies published before the most recent updates to these guidelines employed older terminology and diagnostic criteria, which can make close comparisons difficult.

Treatment for insomnia has also changed markedly in the last 20 years, reflecting greater understanding of the subjective nature of the condition. Many hypnotics and sedatives, particularly benzodiazepines which were prescribed for insomnia for many years, have been shown to reduce sleep quality and increase fall risks in older adults. These negative outcomes have in turn led to a greater emphasis in more recent years on non-pharmacological treatments like cognitive behavioral therapy (CBT) and improved sleep hygiene (Béland et al., 2010; Bourgeois, Elseviers, Van Bortel, Petrovic, & Stichele, 2013; Hägg, Houston, Elmståhl, Ekström, & Wann-Hansson, 2014; MacMahon, Broomfield, & Espie, 2005; Sateia, Buysse, Krystal, Neubauer, & Heald, 2017).

Defining Quality of Life

Quality of life has been used as a benchmark in gerontology since the 1980s, but the term is often poorly defined in research (Dijkers, 2007; Levasseur et al., 2009; Sullivan & Asselin, 2013). When tracing the history of the use of the concept of quality of life in healthcare, Armstrong and colleagues chronicled healthcare providers' movement away from simply collecting symptoms and formulating a diagnosis toward recognizing the importance of the effect of the condition on the patient's world (Armstrong, Lilford, Ogden, & Wessely, 2007). Quality of life instruments were designed to try to measure the "distal consequences" or "downstream" effects of illness, such as impaired mobility and disrupted marital life (Armstrong et al., 2007, p. 581). The

World Health Organization (WHO) defined quality of life as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization, 1997, p. 1). The WHO also noted that it is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of his or her environment (World Health Organization, 1997). Sullivan and Asselin incorporated part of the WHO definition in their (2013) review of literature about general quality of life for elders in long-term care settings, but placed more emphasis on its context: "Quality of life is defined as a perception of satisfaction with life, overall or subjective well-being, and is affected by health status or level of function, relationships with others, or with features of the environment" (Sullivan & Asselin, 2013, p. 191).

However, there is a lot of controversy around quality of life measurement. Despite its potential for bringing a more enlightened perspective to patient care, quality of life has frequently been used as an empty buzz word, or operationalized as a pricing mechanism for health policies, or as a rationale for paternalistic judgements about the lifestyles and well-being of vulnerable and often powerless people. British medical sociologist Ann Bowling has written extensively about quality of life both as a reliable measure of health service outcomes and the frustrations of having to deal with misapplied or poorly designed instrumentation to measure it. (Bowling, 2005). Bowling criticized the negative focus of traditional health outcome indices, which measure deviations from an ideal health and life quality, instead of including broader criteria such as subjective well-being and social health as viewed through the respondents' own perspectives (Bowling, 2005). Similarly, in their scathing critique of quality of life conceptualizations in nursing and medical literature, Moons, Budts and De Geest complained that instruments that were originally designed to measure health status or functional status (most particularly, the Medical Outcomes Study—Short Form 36 (SF-36)), were frequently and erroneously used to measure quality of life, or even a poorly defined health-related quality of life (Moons, Budts, & De Geest, 2006; Ware & Sherbourne, 1992). The term, "health-related quality of life" (HRQoL) has been

coined almost as a specific subgroup within quality of life, although many researchers in this review used the two terms interchangeably.

Another source of controversy in quality of life research is the relative importance of objective dimensions of quality of life, that is, observable life conditions or physical functioning that can be measured with specific tests, compared to subjective dimensions, which refer to the respondents' own perceptions about aspects of their lives. Meeberg's concept analysis of quality of life for patients from a nursing perspective concluded that a subjective component is essential to quality of life and that standardized tools are going to be limited in their effectiveness unless patients are asked directly about their own preferences (Meeberg, 1993). In more recent years, many researchers have maintained that quality of life can ***only*** be evaluated by subjective appraisal of one's life condition. This move toward greater emphasis on subjectivity, and the inclusion of what Bowling calls "patient-based measures" (Bowling, 2005, p. 2), has been accompanied by a growing awareness that quality of life is important to everyone, including people who in the past were considered to have very low life satisfaction or little capacity to evaluate it, such as people with physical or intellectual disabilities, frail older adults and people with dementia. The movement to acknowledge that life can be valuable and satisfying for these previously overlooked populations has required researchers to broaden their definitions and perspectives on quality of life and design new instruments and research protocols that can be used with these groups. For example, Bowling and colleagues' exhaustive research into the effectiveness and validity of different quality of life scales with older adults led them to conclude that too frequently the tools were designed by academics with little input from the population of interest (Bowling, Hankins, Windle, Bilotta, & Grant, 2013). In response, they created one based directly on qualitative interviews with older adults across the UK, in order to represent real-world priorities and views from older adults (Bowling et al., 2013; Bowling & Stenner, 2011).

The existing research about insomnia's effect on quality of life has been based almost exclusively on HRQoL measures. Rombaut and colleagues (1990) developed a 59-item Quality of Life in Insomnia (QoLI) questionnaire based on earlier British sleep assessment tools, as part

of an evaluation of the hypnotic, Zopiclone, in six European countries. However, the scale has not been widely used, and its quality of life criteria were derived from "interviews with experts" and summarized only as physical well-being, mood and mental state and relationships (Kyle, Morgan, & Espie, 2010; Rombaut, Maillard, Kelly, & Hindmarch, 1990, p. 845). Damien Leger and colleagues evaluated the SF-36 as an indicator of quality of life for people with insomnia and then four years later developed the HD-16 as a quality of life instrument specifically for insomnia (Leger, Scheuermaier, Philip, Paillard, & Guilleminault, 2001; Leger et al., 2005). Both studies were based on DSM-4 diagnosis criteria and the second claimed to "control for co-morbid illnesses," although it is unclear how that was done (Leger et al., 2005). The dozen or so intervention studies undertaken in the last 20 years that tested various ways of improving older adults' sleep quality (through exercise, yoga, mindfulness, tai chi, for example) and quality of life invariably used instruments that really measured HRQoL or functional status -- most commonly the SF-36 or the Functional Status Questionnaire – and still drew broad conclusions about participants' quality of life (Berkley, 2017). However, in their extensive literature review of studies of insomnia and HRQoL among the general adult population, sleep specialists Kyle, Morgan and Espie (2010), reflected on the need for accurate quality of life assessment and better design of insomnia studies:

> As a field, we also need to strive for a more sophisticated understanding and conceptualization of QoL and HRQoL, as it relates to insomnia. From the studies reviewed, only a select few actually defined what they were attempting to measure (and these were typically cross-sectional or scale development/validation studies). Moreover, many refer to assessing or improving 'quality of life' when they were actually measuring aspects of HRQoL, using a generic health status measure (Kyle et al., 2010, p. 77)

Kyle, Morgan and Espie noted that the majority of the 12 studies in their review relied on the SF-36 for quality of life assessment, and that this instrument's "reduced sensitivity…to HRQoL impairment in elderly insomniacs… seems to be a recurrent theme" (Kyle et al., 2010, p. 72). The authors speculated that elderly people who have had their sleep problem for a long time may adapt and "recalibrate" in a way that limits insomnia's impact on their functioning, or that the levels of co-morbidity and reduced function associated with normal aging may obscure potential

differences. They also recommended that future research "gather basic qualitative data on the individual experience of [insomnia] treatment" in order to gain insights from the patient's narrative (Kyle et al., 2010, p. 79).

Perhaps it is unfortunate that Moons et al (2006) did not look outside nursing and medical literature for a better model of quality of life, because 20 years earlier in environmental psychology, Lawton had developed one of the most comprehensive models of quality of life, and one that addresses many of the problems Moons et al identified. Lawton's quality of life model is aimed at older adults and grew out of his work with the Ecological Theory of Aging. It has been the basis of much quality of life research and instrumentation development for older adults and particularly for people with dementia (Albert & Logsdon, 2000; Bowling et al., 2015; Logsdon, Gibbons, McCurry, & Teri, 1999). Lawton's model, which he initially titled, "the good life", divides aspect of human life into four interacting sectors: behavioral competence, psychological well-being, the objective environment, and perceived quality of life (Lawton, 1983a) as shown in Figure 4 on page 42.

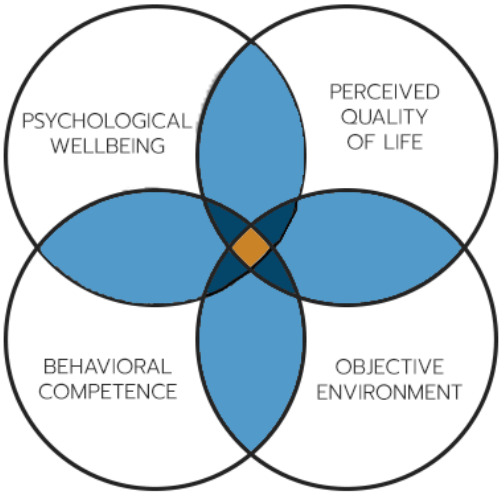


Figure 4. Four Sectors of Quality of Life.

Adapted from Lawton, M (1983). Environments and other determinants of well-being in older people. The Gerontologist, 23(4), 349–357.

Lawton maintained that quality of life was a multidimensional concept, and that physical health was only one of many related domains that it encompassed (Lawton, 1991). He defined the four sectors as follows:

- Behavioral competence represents the social-normative evaluation of the person's functioning in the health, cognitive, time-use and social dimensions. These included roles performed, activities of daily living and cognition.
- Psychological well-being is the person's subjective evaluation of the overall quality of his or her inner experience.
- Perceived quality of life is the set of evaluations a person makes about each major domain of his or her life.
- Objective environment refers to all aspects of the person's living situation, including natural or manufactured elements, social support networks, and the social-institutional and cultural forces to which the person is exposed (Lawton, 1983a, 1991).

For the purposes of this study, quality of life was defined according to Lawton's Four Sectors. Lawton's quality of life model knits neatly with the Ecological Theory of Aging by combining objective (behavior competence and objective environment) and subjective (psychological well-being and perceived quality of life) perspectives on both the person and the environment. Lawton maintained that both objective and subjective measures were necessary for social planning for healthy behavior and for sound, beneficial design of living environments. He also maintained that these objective measures provided an anchoring point from which individual perceptions could deviate, citing the example of a physically disabled person who cannot walk, but has compensated so completely both in behavior (using a wheelchair) and psychology (no feeling of inferiority) that the disabled status is negated (Lawton, 1991). In this theoretical example, the person is functioning in the Ecological Theory of Aging's zone of maximum performance potential where personal competence and environmental press are in balance.

THEORETICAL FOUNDATIONS

The Spielman 3P model was used as a lens to examine the factors that past researchers have determined lead to the development of insomnia and to demonstrate how these factors function as sources of environmental press or personal competence under Lawton and Nahemow's Ecological Theory of Aging. These two models were explained in detail in Chapter 1, and so are only briefly summarized below.

The Ecological Theory of Aging.

M. Powell Lawton developed the Ecological Theory of Aging in the 1970s, as part of his decades-long research into the effect of living environments on older adults' ability to cope with aging and increasing dependence and their quality of life. Lawton was a behavioral psychologist and an early advocate for living spaces designed for frail elderly people, and particularly people

with Alzheimer's disease (Lawton, 1990; Lawton & Nahemow, 1973; Saxon, 2001). The Ecological Theory of Aging describes the interdependence of person and environment as a set of personal competencies set against "environmental press" or the demands and contexts of a living environment (Lawton & Nahemow, 1973). Lawton and Nahemow's schematic of the theory (see Figure 6) shows a range from low competence and weak environmental press to high competence and strong environmental press, with a line representing an ideal adaptation level running roughly up the middle between the two. On either side of the adaptation level are two zones: zone of maximum comfort and the zone of maximum performance potential, where, according to Lawton and Nahemow, established competence and environmental adaptation result in good quality of life (Lawton & Nahemow, 1973).

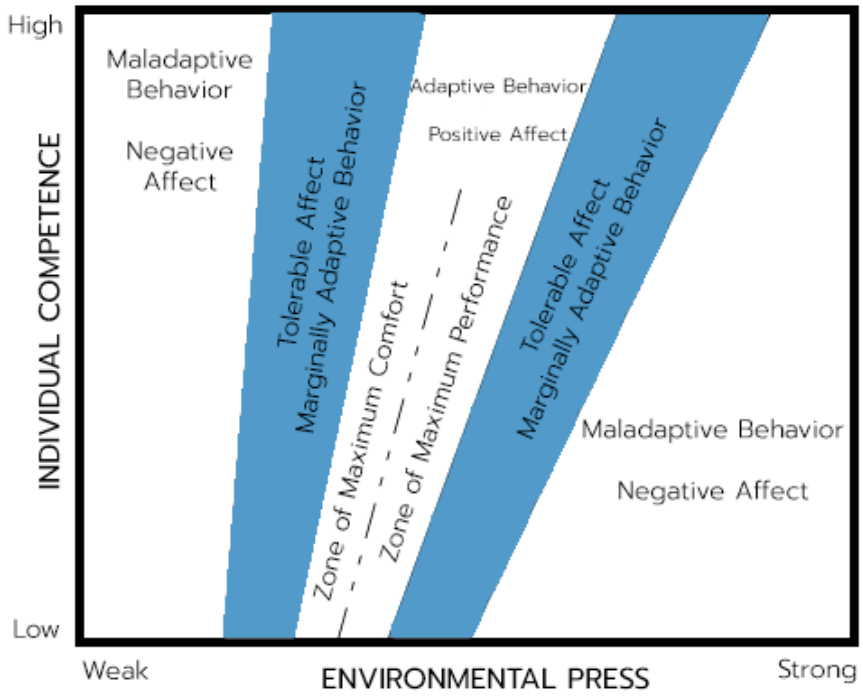


Figure 5. The Ecological Theory of Aging.

> Adapted from Lawton, M., & Nahemow, L. (1973). Ecology and the aging process. In C. Eisdorfer & M. Lawton (Eds.), *Psychology of adult development and aging*. Washington, D.C: American Psychological Association.

The Ecological Theory of Aging informed the evaluation of the insomnia factors identified in this literature review through the Spielman model. Later it will also support analysis of participants' experiences at varying levels on the trajectory of dependency as functions of environmental press and personal competence.

The Spielman 3P Model of Insomnia.

Spielman and Glovinsky identified three risk factors for insomnia in the general adult population: Predisposing factors, Precipitating factors and Perpetuating factors, (see Figure 3) which together show how insomnia occurs acutely and how it frequently develops into a chronic, self-perpetuating problem (Perlis et al., 2011; Spielman et al., 1987).

- **Predisposing factors**: Some psychological or biological characteristics increase vulnerability, or predisposition to sleep difficulties (e.g., female gender, anxiety, hyperarousal).
- **Precipitating factors**: Life events and medical, environmental or psychological factors can trigger acute insomnia (e.g., divorce, death of a significant other, illness, medication, familial or occupational stress).
- **Perpetuating factors**: Behaviors or beliefs maintain or exacerbate insomnia after the precipitating event or trigger is resolved. Perpetuating beliefs and thoughts include fears of sleeplessness and excessive worries about daytime consequences of sleep (Spielman et al., 1987).

Applying the 3Ps to Older Adults

Under the Spielman 3P model, the first two types of factors (predisposing and precipitating) represent a stress-diathesis conceptualization of how insomnia comes to be expressed, while the third factor (perpetuating) represents how behavior makes the condition chronic (Perlis, Ellis, Kloss, & Riemann, 2017). The model was intended for the general adult population, and Perlis et al noted that predisposition could range across the biopsychosocial spectrum, from for example genetic predisposition, or increased basal metabolic rate, to excessive rumination, to family dynamics that require sleeping on a non-preferred schedule (such as during childrearing). They also note that while the 3Ps have not been empirically tested, it is plausible that insomnia represents an adaptive response to stress and part of the fight-flight response, and that predisposition varies across the lifespan (for example, with pregnancy and hormonal changes, new bed partner, or aging) (Perlis et al., 2017). Earlier research studies employing the Spielman model regularly cited age, female gender, and a tendency to worry, or an anxious disposition as most common predisposing factors (Jungquist, 2011; Krishnan & Hawranik, 2008b; Morin & Espie, 2004), and these factors apply to the older adult population as well. However, the insomnia triggers, or precipitating factors, for older adults are different from those routinely applied to

people aged 18-60. Junquist noted that in the general adult population, insomnia is more prevalent among people with chronic medical conditions, specifically heart disease, breathing problems, and chronic pain; and that stress from work-school events, family issues or illness are the most common precipitating factors (Jungquist, 2011). Older adults, on the other hand, experience stresses and life changes that are frequently perceived as losses – bereavement, retirement, onset of illness or disability in self or partner. In the chapter in *Case Studies in Insomnia,* on the older adult, Flaxman (1991) noted:

> Older insomniacs are likely to be dealing with different life issues than younger insomniacs. Issues such as understanding one's own aging, death and dying, and coping with chronic illness and disability are important for this population (Knight, 1986). For some clients, the stress that these life cycle issues can create must be addressed in treatment, rather than other issues that are more common in a younger population. (Flaxman, 1991, p. 238).

Similarly, Khan-Hudson and Alessi noted the importance of extra considerations when evaluating sleep and quality of life for older adults, including the physical living environment, the individual's autonomy, how time is used, and satisfaction with care (Khan-Hudson & Alessi, 2008). These considerations are strongly linked to stages on the trajectory of dependency and changes that affect them can precipitate insomnia.

The third P, perpetuating behaviors, are those that people adopt in order to cope with sleeplessness and include extending time spend in bed to try to sleep more or taking naps. Both older and younger adults are similarly vulnerable to dysfunctional cognitions about sleep or maladaptive habits, but older adults are less likely to seek help or advice from a healthcare provider than younger adults, and they face additional bias because of provider ignorance about insomnia in older people (Institute of Medicine, 2006; Reid et al., 2006).

Because this literature review focused on older adults, the factors *predisposing* older adults to insomnia that were examined were advanced age, female gender, and a history of anxiety. In preliminary work three *precipitating* factors for insomnia that were mentioned by participants most frequently: death of a spouse, institutionalization, including moving to assisted living or a retirement community, and the onset or significant worsening of a chronic illness. The most

significant and recurring *perpetuating* factors in the literature for older adults are: lack of understanding or attention to insomnia from healthcare providers, dysfunctional beliefs and cognitions held by the older adult, and maladaptive habits. If these factors are examined through the lens of the Ecological Model, they can be considered extensions of Lawton's personal competencies or sources of environmental press that affect sleep quality. The predisposing factors relate to the individual's personal competences as a function of older age such as age or gender. The precipitating factors are frequently environmental presses, such as bereavement or institutionalization. The perpetuating factors include both environmental presses (lack of understanding by healthcare providers) and personal competences (dysfunctional cognitions).

PREDISPOSING FACTORS AND PERSONAL COMPETENCIES

In their Ecological Theory of Aging, Lawton and Nahemow defined the concept of competence as innate functional capabilities, and noted that competence has biological, psychological and social components (Lawton & Nahemow, 1973; Nahemow, 2000). The factors that are commonly reported as predisposing people to insomnia – age, female gender and anxiety -- can be viewed as competences that interact with environmental press leading to insomnia.

Age

Age is probably the single most important variable determining the quality and duration of sleep (Morin & Espie, 2004). Sleep duration and quality varies across the human lifespan and standards of "normative" sleep are affected by environments, societal roles, cultural patterns and living arrangements as well as by physiological changes associated with age (Morin & Espie, 2004; Redeker, 2011). Contrary to popular beliefs about aging, research has shown that healthy older adults and younger adults require comparable amounts of sleep but that multiple health, social and environmental risk factors make achieving that need much more difficult as people age (Hirshkowitz et al., 2015; Petrov et al., 2014). Insomnia prevalence rises with age but the reasons

for this increase are complex. Epidemiological studies of insomnia in older adults in journals and textbooks have used varying methods, diagnostic criteria and measurements over the last 30 years and made varying, sometimes conflicting conclusions about the role of physiological aging itself (Ancoli-Israel, 2004; Morin & Espie, 2004; Ohayon, 2002; Voyer et al., 2006). Figure 7 shows the increase in three types of insomnia across the lifespan, and how sleep maintenance, in particular, frequently proves more difficult for older adults.

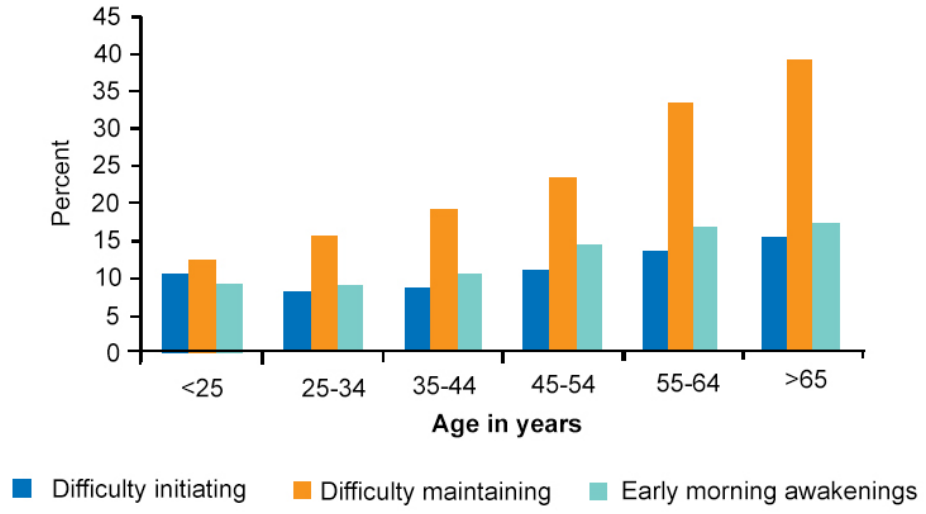


Figure 6. Sleep Disturbances by Type Over the Lifespan.

Adapted from Ohayon, M., & Reynolds, C. (2009). Epidemiological and clinical relevance of insomnia diagnosis algorithms according to the DSM-IV and the International Classification of Sleep Disorders (ICSD). *Sleep Medicine*, *10*(9), 952–960.

Older adults' sleep has been described as more "fragile" (Petrov et al., 2014, p. 527), more "easily disrupted" (Ancoli-Israel & Cooke, 2005, p. S264), and "more disjointed" (Ruiter, Vander Wal, & Lichstein, 2010, p. 271) than that of younger adults. How much of this fragility or disjointedness is due to external, potentially modifiable factors such as stress, pharmacology, pain, nocturia, or poor environment is difficult to ascertain. However, there are some age-related physiological changes that all humans experience that affect sleep. Older adults' sleep architecture, the structure of their sleep cycles, differs from that of younger adults in that they spend less time in the deeper Slow-Wave Sleep (SWS) stage and have fewer, briefer episodes of Rapid Eye Movement (REM) sleep. Because older adults spend more time in the earlier, lighter, sleep stages (1 and 2), they can experience greater numbers of arousals (Ancoli-Israel & Cooke, 2005; Bliwise, 1993; Morin & Espie, 2004; Petrov et al., 2014).

In one of the most rigorous and frequently cited epidemiological studies of insomnia in older adults, 42% of community-dwelling older adults (N=6,899) reported difficulty in initiating

and maintaining sleep (Foley et al., 1995). In a three-year follow-up study of these elderly individuals, the authors noted that of the 2000 survivors who had reported chronic difficulties at baseline, about 50% no longer had insomnia symptoms at the three-year follow up, and the reduction in sleep complaints was associated with improvement in health. The authors concluded that **aging alone does not account for the sleep complaints of the older adult**; rather, it is the associated health problems that are associated with poor sleep (Ancoli-Israel & Cooke, 2005; Foley, Monjan, Sominsick, Wallace, & Blazer, 1999).

The empirical evidence for the role that age plays in sleep quality is inconclusive, as research studies have not effectively controlled for comorbidities. Another reason the results are mixed maybe the use of instruments that were normed on younger adults and that may fail adequately to consider the unique experiences of older adults. This study attempted to capture this unique experience by eliciting the voice of those older adults living through these experiences.

Gender

Many studies have reported that women experience more insomnia and different types of insomnia (Ancoli-Israel & Cooke, 2005; Foley et al., 1999; Ohayon & Vecchierini, 2005; Petrov et al., 2014) but theories about the reasons for these gender differences have been inconclusive and occasionally contradictory. Minarik noted that until the late 1980s, 75% of sleep studies included only men, and that studies that did include women failed to address sex or gender differences (Minarik, 2011). Female gender is almost routinely listed as a predisposing factor for insomnia (Armstrong & Dregan, 2014; Foley et al., 1995; Ohayon, 2002; Petrov et al., 2014; Spielman et al., 1987) with little analysis of why this is the case. Hormonal changes experienced in menopause cause sleep disruption in many women and for many years, changing levels of estrogen had been suggested as possible causes of female insomnia, but improvements in neuroscience and electroencephalogram (EEG) technology have shown that there are gender differences in sleep architecture (Minarik, 2011). Minarik noted that recent analyses of EEG data using spectral methods (an alternative to the standard means of measuring Short Wave Sleep) showed women to

have less slow-wave activity than men, which is consistent with patterns of wakefulness and lower rates of growth hormone release in older women than older men (Minarik, 2011). Ohayon and colleagues' meta-analysis of sleep parameters from childhood to old age noted the following gender differences in older adults:

- Women spend less time in Stage 2 sleep than aged-matched men;
- Women have longer sleep latency than aged-matched men;
- Age-related declines in sleep efficiency were more significant in women;
- Women have longer total sleep time (TST) than aged-matched men (Minarik, 2011; Ohayon, 2002; Ohayon & Vecchierini, 2005).

Similarly, Zhang and Wing's rigorous meta-analysis of 31 studies of sex differences in insomnia found that a "female excess" in the risk of insomnia was higher in larger and better quality studies, and that the trend of female predisposition was consistent and progressive across age, with more significance in the elderly (Zhang & Wing, 2006). In contrast, Bixler and colleagues (2009) found no differences in sleep latency or Stage 2 sleep between men and women, and in fact concluded that women sleep better than men across the lifespan, perhaps "to protect women from the profound demands of infant and childcare for most of mankind's history" (Bixler et al., 2009, p. 226). When Phelan and colleagues examined changes in sleep quality for 115 community-dwelling older women using growth curve modeling to analyze trajectories of sleep quality over time, they found two different patterns: good but declining sleep quality and disrupted sleep quality (Phelan, Love, Ryff, Brown, & Heidrich, 2010). Higher psychological well-being, fewer illnesses and lower depression scores at baseline predicted reduced odds for membership in the disrupted group, which is consistent with other studies looking at the effects of depression and anxiety on sleep (Phelan et al., 2010; Ramsawh, Stein, Belik, Jacobi, & Sareen, 2009; Spira et al., 2012). Both Phelan et al, and Bixler et al suggest that women's traditional predisposition towards insomnia may really be a predisposition towards anxiety and depression, presenting as sleeplessness (Bixler et al., 2009; Phelan et al., 2010).

None of the studies appeared to consider the demographic issues of gender in older adults; namely that older women significantly outnumber older men, and that any female bias in the reporting of insomnia may be because there are more women in the population (Administration on Aging, 2018). Furthermore, many older women are experiencing several of the common predisposing and precipitating factors at the same time, but this multiplied effect is not easily identified with quantitative sleep instruments.

Anxiety

Epidemiological data shows that insomnia is a risk factor for later development of psychiatric disorders, including mood disorders, anxiety, and substance abuse disorders. At the same time, large percentages of people with psychiatric issues have insomnia (Ebben & Spielman, 2008; Mai & Buysse, 2010; Monti & Monti, 2000; A. Spira, Stone, Beaudreau, Ancoli-Israel, & Yaffe, 2009; Wetherell, Le Roux, & Gatz, 2003). Early insomnia studies, including Spielman and Glovinsky's initial model, characterized a typical person with insomnia as anxious, worried and ruminating, and this disposition was presumed to be more pronounced in older people and in women (Ford & Kamerow, 1989; Hauri & Fisher, 1986; Spielman et al., 1987). Many of these earlier studies investigating the connection between insomnia and anxiety used a mix of subjective and objective assessments but as with insomnia, the diagnostic criteria and measurement of anxiety have been refined in the last 30 years. The American Psychological Association's *Diagnostic and Statistical Manual* (4th edition) characterized general anxiety disorder (GAD) as an inability to control excessive worry or anxiety for more than six months, and symptoms included restlessness, irritability, fatigue, difficulty concentrating, *and sleep disturbance – difficulty falling asleep, staying asleep or unsatisfying sleep,* and although the definition and diagnostic criteria were further refined in the DSM-5, sleep disturbance remains a key component (American Psychiatric Association, 2013). GAD affects all four areas of insomnia: reduced total sleep times, early morning awakenings, poor sleep efficiency and long sleep latency, and has been shown to increase older adults' risk of memory problems, physical disability and mortality and has significant

negative effects on quality of life (G. Brenes et al., 2009; Harvard Medical School, 2009; McEnany, 2011; Wetherell et al., 2003). More recent studies of insomnia and anxiety describe the association between the two using the concept of hyperarousal, which Ebben and Spielman defined as "a combination of physiological, mental, and behavioral traits associated with arousal, including a strong startle reaction to loud noises, rumination, conscientiousness, and negative response to unexpected events" (Ebben & Spielman, 2008, p. 244). Under this theory, hyperarousal, along with certain personality traits, including neuroticism, internalization and perfectionism (Lichstein et al., 2016; Petrov et al., 2014) leads to excessive rumination which evolves into a perpetuating factor for the insomnia as the person becomes more worried about his or her lack of sleep (see Perpetuating Factors below).

In their study of anxiety and sleep quality in older women, Spira and colleagues suggested anxiety was more prevalent in older adults than either depression or dementia (Spira et al., 2009), but despite the strong connections between insomnia and anxiety there has been little work on GAD in older adults. Sleep medicine texts have noted the problem of overlap with depression and major depressive disorder in older adults, and perceived difficulties in controlling for one condition over the other (Ebben & Spielman, 2008; Mai & Buysse, 2010; Wetherell et al., 2003). However, some of the most recent studies have attempted to account separately for the effects of anxiety vs insomnia (Brenes et al., 2009) or to determine which specific type of insomnia (e.g., early morning awakening or long sleep latency) it is that anxiety affects (Gould et al., 2018).

In one of the few studies incorporating the up-to-date DSM-5 revised criteria for both GAD and insomnia, Potvin et al assessed sleep quality in over 2000 older adults and attempted to differentiate effects of four different types of anxiety disorder and either major or minor depressive episodes (Potvin et al., 2014). They concluded that GAD was significantly associated with a greater likelihood of daytime dysfunction, due to daytime sleepiness and lack of enthusiasm to complete tasks (Potvin et al., 2014). Another recent study looking at the relationship between chronic pain, anxiety and depression in older adults found that it was anxiety that had the strongest

relationship to insomnia, rather than the intensity of the pain, or depression (Dragioti, Levin, Bernfort, Larsson, & Gerdle, 2017).

Summary of Predisposing Factors

Of the three predisposing factors, it is anxiety that has the strongest empirical support, and may actually be the key trait underlying both the state of hyperarousal that delays sleep onset, as well as the rumination and worry that perpetuates insomnia after the precipitating factor that triggered the sleep problems has been resolved. The most rigorous and current literature has agreed that chronological age itself does not predispose a person towards insomnia; rather the responsibility lies with the other challenges aging people face, including chronic illnesses, stresses and psychosocial issues associated with aging. It seems reasonable to conclude that gender, too, is not a true predisposing factor, and that it is other aspects of aging that older women face that lead to insomnia. However, anxiety is a significant factor, as it reduces personal competence needed to adapt to the challenges of aging. Anxiety also creates an increased vulnerability to Lawton and Nahemow's environmental press, as an anxious person is going to be lower down on the Ecological Model's scale and more sensitive to environmental changes and stresses.

PRECIPITATING FACTORS AND ENVIRONMENTAL PRESS

Precipitating factors are life events and/or medical, environmental or psychological stresses that can trigger acute insomnia. Work stresses, family issues and health concerns are the common precipitating factors for younger adults. But older adults are frequently experiencing losses, health issues and environmental changes that create different kinds of stress. The factors that are commonly reported to precipitate insomnia in older adults are bereavement, the onset or significant worsening of a chronic illness, and institutionalization or move to a more restrictive living situation. All of these create environmental press that requires adaptation and adjustment.

Loss of spouse/bereavement

The death of a spouse is a stressful, life-changing event for anyone but can be especially traumatic for older couples who have been together for many years and may be heavily co-dependent on each other physically and emotionally. The death of a spouse or life partner is accompanied by changes in lifestyle and status, including reduced financial security, perceived personal safety, and freedom of action (Monk, Germain, & Reynolds, 2008; Simpson, Allegra, Ezeamama, Elkins, & Miles, 2014). Bereavement is defined as the loss of a loved one by death, while grief is the emotional reaction to a bereavement, but both experiences are strongly linked to insomnia (Foley et al., 1999; Monk et al., 2008; Naef, Ward, Mahrer-Imhof, & Grande, 2013; Petrov et al., 2014; Pigeon & Perlis, 2008; Richardson et al., 2015; Simpson et al., 2014). Several studies reported insomnia in 30-50% of subjects with bereavement, and the level of sleep disturbance was higher than in that of control groups without bereavement (Pigeon & Perlis, 2008; Richardson et al., 2015). While bereavement and the more extreme diagnosis of "complicated grief" are frequently linked to depression, even people without depression experience insomnia after the death of a loved one (Monk et al., 2008; Simpson et al., 2014).

Naef and colleagues' integrative review of 39 studies of the experience of bereavement for older adults noted that conjugal bereavement in later life can be especially complicated because of concurrent losses, failing health and increasing dependence (Naef et al., 2013). The subjects in the reviews they examined reported difficult changes to daily routines and notable health problems, of which sleep disruption was the most prominent concern. One study reported that 19% of the widows suffered from a disrupted sleep pattern up to two years after the loss (Naef et al., 2013). Similarly, in their in-depth investigation of the links between widowhood and health behaviors using the Changing Lives of Older Couples (CLOC) data, Carr, Nesse and Wortman, examined five aspects of health behavior: sleep patterns, alcohol consumption, smoking, body weight and physical activity (Carr, Nesse, & Wortman, 2008). They focused on two dimensions of sleep: daily sleep (or total sleep time) and sleep medication use. At the 6-month follow up their results showed that widowed women slept less, used sleep medication more frequently, were more likely to

smoke, smoked more cigarettes per day and lost more weight than their still-married peers. In contrast, the widowed men in their study had adopted more active lifestyles and lost weight. However, these changes did not persist over the long term. By the 48-month follow-up, widowed persons were no different from their married peers (Carr et al., 2008). Carr and colleagues discussed possible reasons for the gender differences in their results, suggesting that the demographic make-up of their sample, (68% female) and the lower socio-economic status of many older women may have been significant factors in the their reactions to spousal bereavement (Carr et al., 2008).

Bereavement is an experience that involves both of Lawton and Nahemow's core concepts in the Ecological Model. People with high personal competencies can still struggle with the loss of a spouse (or a child) and the resulting grief, loneliness, loss of familiar routines, and possible financial strain create stronger environmental press. Many bereaved older adults are also living with other precipitating factors: for example, they may have been caring for their spouse with a chronic illness or have one themselves.

Chronic illness

As diagnosis and measurement of insomnia has been refined, and as more is understood about the connections between health behaviors, chronic illnesses, and social stresses, researchers have begun to study insomnia in conjunction with related physical and psychological complaints. Early insomnia instruments asked about pain and nocturia and presence of comorbidities (Buysse et al., 1989; Ford & Kamerow, 1989; Rombaut et al., 1990; Spielman et al., 1987), but more recent works have examined insomnia as both a symptom of chronic illness and a result of it. Cardiovascular disease, diabetes, chronic obstructive pulmonary disease, depression and arthritis have been strongly linked to insomnia in older adults, and more recent studies noted that sleep complaints increase in prevalence with aging in a pattern that tracks the increase in medical conditions and medication use (Barczi, 2008; Foley et al., 2004; Lichstein et al., 2016). In addition to the discomfort and stress of a chronic condition, many of the medications taken to treat it,

including beta blockers, bronchodilators, calcium channel blockers, corticosteroids, decongestants, stimulating antidepressants, and thyroid hormones are stimulating and can cause insomnia symptoms (Ancoli-Israel & Cooke, 2005; Ohayon, 2002).

Barczi noted that between 89% and 94% of people over age 65 take prescription medications and nearly 40% take more than five, which puts them at risk for polypharmacy and the cascade effect, in which patients are given medications to treat side effects of other medications (Barczi, 2008). Insomnia is an especially harmful pharmacological side effect as medications to treat it, particularly benzodiazepines, have been shown to worsen the condition over time and are not recommended for older adults (Bourgeois, Elseviers, Van Bortel, Petrovic, & Vander Stichele, 2014; Hägg et al., 2014; Sateia et al., 2017).

Institutionalization/change in living situation

Insomnia is intricately connected with institutionalization of older adults and with their progression along the trajectory of dependence. Insomnia and disordered sleep are frequently key factors in decisions to institutionalize older adults, particularly when the older person has some form of dementia (Kaufmann et al., 2013; Pollak & Perlick, 1991). Pollack and Perlick interviewed caregivers about their decision to institutionalize elderly relatives and found that over 70% of caregivers cited sleep disturbance as a key factor, because their own sleep was affected, and 20% specified it as their primary reason (Choi & Irwin, 2008; Pollak & Perlick, 1991). Families caring for elderly relatives reported that even with mild cognitive impairment or early dementia, they could take care of the relative at home until nighttime wandering and confusion becomes too disruptive to the caregivers and family as a whole (Bliwise, 1993; Pollak et al., 1990).

At the same time, insomnia frequently develops as a result of institutionalization, due to stresses, environmental change, loss of familiar spaces and routines, and anxiety (Eser, Khorshid, & Cinar, 2007; Martin & Ancoli-Israel, 2008; Rao et al., 2005; Valenza et al., 2013). In fact, relocation in general, even if not specifically to a long-term care facility or nursing home, has been shown to increase anxiety and affect sleep quality in older adults (George, 1980; Lawton, 1983a).

Voyer and colleagues noted that the typical nursing homes, with long corridors, shared rooms, televisions and staff shift changes, are not conducive to sleep (Voyer et al., 2006). Several of the classic studies linking nursing home placement to mortality do not directly reference sleep disorders (Brink & Kelley, 2015; Flacker & Kiely, 2003) but they do list falls as a risk factor, and several specifically sleep-oriented studies have linked insomnia to fall risk (Hanford & Figueiro, 2013; Krishnan & Hawranik, 2008b; Lee et al., 2009; Martin & Ancoli-Israel, 2008; Valenza et al., 2013). In addition, several studies have linked insomnia to increased mortality risks, either in rehabilitation centers, acute care facilities or the community (Cohen-Mansfield & Perach, 2012; Dew et al., 2003; Gamaldo et al., 2016; Martin et al., 2011). Improving sleep for older adults in any institutional setting should be a priority for improved quality of life.

Summary of Precipitating Factors

While the question of whether the effects of age, gender, and/or anxiety really predispose older adults towards insomnia has been debated, the effects of the precipitating factors described in this review are almost universally acknowledged in research literature. There is strong empirical support that bereavement, chronic illness and institutionalization or change of living situation precipitate the onset of insomnia symptoms. What the literature seems not to have acknowledged, is how common it is for an older adult, particularly an older woman, ***to experience all three of these precipitating factors within a short period of time.*** Like Irene in the introductory case study, who moved to a continuing care community after the death of her husband while dealing with signs of early cognitive impairment, many older adults face declining health and social changes that require steps down the trajectory of dependency. However, many of these precipitating factors are not caught in sleep assessment tools that only ask for events and sleep patterns occurring within the last month. Qualitative interviews are necessary to enable older adults to put their insomnia experience in the context of their larger experience of aging. These stressful, life-altering events create quite strong environmental press and require adaptations on many different levels. Acute insomnia is not surprising in these circumstances, but as the person adapts, the insomnia normally

resolves. The factors that perpetuate the insomnia and significantly affect health and quality of life are examined in the next section.

PERPETUATING FACTORS

Perpetuating factors are maladaptive behaviors or dysfunctional beliefs that maintain or exacerbate insomnia after the precipitating event or trigger is resolved. People adopt maladaptive behaviors in order to cope with sleeplessness, and they include spending longer time spend in bed to try to sleep more or taking naps. Dysfunctional beliefs or unrealistic expectations about sleep, (e.g., "I must get 8 hours of sleep to feel refreshed"), misconceptions about the causes of insomnia (e.g., "I believe it is the result of a chemical imbalance"), and diminished perceptions of control (e.g., "one bad night will disrupt me for the whole week") can prolong insomnia even after acute physical or environmental problems are resolved (Carney, Edinger, Manber, Garson, & Segal, 2007; Morin et al., 1993; Spielman et al., 1987). Both older and younger adults are similarly vulnerable to dysfunctional cognitions about sleep or maladaptive habits, but older adults are less likely to seek help or advice from a healthcare provider than younger adults, and they face additional bias because of provider ignorance about insomnia in older people (Institute of Medicine, 2006; Reid et al., 2006). This review will examine three perpetuating factors: lack of attention and understanding from healthcare providers, maladaptive habits, and dysfunctional beliefs about sleep.

Lack of attention or understanding from HCPs to insomnia

Sleep disorders are frequently overlooked in many primary care settings, particularly for older adults, with whom it can be difficult to separate sleep issues from other medical and psychiatric issues (Benca, 2005; Hidalgo et al., 2012; Hirshkowitz et al., 2015; Krishnan & Hawranik, 2008). In a systematic review of randomized controlled trials of both behavioral and pharmacological insomnia treatments published between 1974 and 2004, Benca found that patients' needs for insomnia treatment remained unmet because of a number of issues:

- Inadequate physician training in insomnia;
- Time-constrained physician office visits;
- Lack of discussion about sleep problems during patient consultations;
- Belief among patients and physicians that sleep complaints are not important;
- Perception by physicians that treatments for insomnia are ineffective or risky;
- Lack of evidence that treating insomnia improves outcomes of comorbid conditions (Benca, 2005).

Reid and colleagues examined the relationship between sleep problems and health-related quality of life for 1500 adults between 62 and 100 years old through a five-item sleep questionnaire, the SF-12, and a medical chart review (Reid et al., 2006). They found that 68.9% of subjects reported one sleep complaint and 40% had two or more, but even when all five items of the sleep questionnaire were endorsed, a sleep complaint was noted in the patient's medical chart only 19.2% of the time (Reid et al., 2006). Questions regarding sleep are not an integral component of most clinical evaluations, despite the fact that sleep complaints predicted the general physical- and mental health-related quality-of-life status in elderly populations with comorbid medical and mental illnesses (Dew et al., 2003; Pollak et al., 1990; Reid et al., 2006). Voyer et al agreed that sleep is incompletely assessed, and quoted Dement's earlier conclusion that "physicians abstain from asking question about sleep problems because they often feel incapable of alleviating them" (p.4) particularly among nursing home residents, who were the subject of their investigation (Voyer et al., 2006). Voyer et al also noted the frustration of having hypnotic prescriptions being the first therapy considered, (even though there were alternatives to benzodiazepines that could improve residents' sleep and be given by nurses or other health care providers) and complained that none of the nursing homes included had a sleep hygiene program (Voyer et al., 2006).

The need for greater physician awareness and more public education about the importance of good sleep at all ages was a key point in the 2006 reports from the Institute of Medicine's Committee on Sleep Medicine and Research and in the National Institute of Health's State-of-the

Science Conference Statement on the manifestations and management of chronic insomnia in adults (Institute of Medicine, 2006; National Institutes of Health, 2005). Clearly, people are not going to get proper treatment until health care providers are educated about the importance of sleep and the best treatments for insomnia. Lack of understanding from healthcare providers can also reinforce people's unrealistic beliefs about sleep.

Dysfunctional cognitions

The most significant and deeply entrenched perpetuating factors for insomnia are the beliefs about sleep and the sleep behaviors of the individual concerned. Short-term or situational insomnia normally abates after the precipitating event resolves and/or the individual adapts to the environmental change(s), but some people develop dysfunctional beliefs, or unrealistic expectations about sleep that take the insomnia to a more serious, chronic level (Carney et al., 2007, 2010; Ellis, Hampson, & Cropley, 2007; Morin & Espie, 2004). Morin noted that the insomnia is more likely to persist over time if a person interprets the situational insomnia as a sign of danger or loss of control and begins to monitor the sleep loss and worry about its consequences (Morin & Espie, 2004). This state of worry and anxiety becomes linked to the experience of trying to go to sleep and creates a state of hyperarousal, both physical and emotional, that directly impedes sleep, and becomes a problem in itself (Morin & Espie, 2004; Spielman et al., 1987). Palagini and colleagues described this state as a collection of maladaptive cognitions, which include worry, selective attention monitoring, misperception of sleep, safety behaviors, unhelpful beliefs, and expectations about sleep (Palagini et al., 2015).

Much of the research about dysfunctional beliefs as perpetuating factors for insomnia has involved the Dysfunctional Beliefs About Sleep (DBAS) questionnaire, which has been used to demonstrate that people with insomnia have more pathological beliefs about sleep than gender- and age-matched subjects without sleep problems (Carney et al., 2007; Edinger et al., 2000; Morin et al., 1993). The DBAS was developed out of clinical experiences with insomnia patients and their false, or inaccurate beliefs about the condition, including unrealistic sleep expectations (e.g.,

"I must get 8 hours of sleep to feel refreshed"), misconceptions about the causes of insomnia (e.g., "I believe it is the result of a chemical imbalance"), and diminished perceptions of control (e.g., "one bad night will disrupt me for the whole week") (Morin, Vallières, & Ivers, 2007). These beliefs heighten anxiety and lead individuals to adopt coping strategies that are frequently detrimental and counter-productive (Carney et al., 2010; Spielman et al., 1987). The similarities between these dysfunctional cognitions and general anxiety disorder led Harvey (2002) to develop a cognitive model of the maintenance of insomnia based on the cognitive models for anxiety disorder. Harvey's model proposed that the individual becomes trapped by these negative cognitive processes into becoming more absorbed by and anxious about the sleep problem, and then tends to overestimate the daytime dysfunction and underestimate total sleep time. Harvey suggested that, as in treatments for anxiety, insomnia treatment should not focus on increasing sleep time, but on helping the individual take back a sense of control by correcting erroneous beliefs about sleep and eliminating the use of counterproductive coping behaviors (Harvey, 2002).

Maladaptive behaviors

These dysfunctional cognitions lead the patient to adopt maladaptive coping strategies and behaviors, such as extending the time spent in bed to make up for a poor night's sleep, that further disrupt sleep (Carney et al., 2007; Palagini et al., 2015; Spielman et al., 1987). These beliefs and behaviors may also be responsible for the limited efficacy of hypnotics and sedatives, especially with older adults. Much of the recent guidance for treating insomnia, using cognitive behavioral therapy (CBT) and good sleep hygiene, strongly recommended that these dysfunctional beliefs be addressed in therapy in order to ensure that the behaviors are not repeated in future stressful conditions (G. A. Brenes, Danhauer, Lyles, Anderson, & Miller, 2016; Ebben & Spielman, 2008; McCurry, Logsdon, Teri, & Vitiello, 2007).

Summary of Perpetuating Factors

Harvey's model neatly codified the negative spiral that is created as people with insomnia begin to transfer the anxiety and stress from their life experience or a precipitating event to their own sleep. The research around dysfunctional beliefs and cognitions emphasized the importance of psychological assessment and patient education in treating insomnia, for the relatively few people who are able and willing to seek medical advice about the condition. A combination of greater awareness among healthcare providers of the consequences of insomnia and the most effective ways to treat it would be one useful step towards breaking that negative spiral and improving older adults' quality of life.

CONCLUSION

This review has used the Spielman 3P model of insomnia as a lens through which to examine scholarly literature around the factors reported to affect quality of life for older adults experiencing insomnia. Lawton and Nahemow's Ecological Theory of Aging allows us to see these insomnia factors as personal competencies and sources of environmental press that demonstrate how insomnia affects older adults' quality of life. Insomnia may be an adaptation to environmental press and internal anxieties, but it pushes people away from Lawton and Nahemow's zones of maximum performance potential and maximum comfort. The Spielman model has been well accepted by both patients and researchers and is compatible with the recommended behavioral therapy for insomnia based on sleep restriction and cognitive behavior therapy (Perlis, Corbitt, & Kloss, 2014; Perlis et al., 2011; Spielman et al., 1987). Through the factors outlined in the model it is possible to see the patterns and progressions in the scholarly literature around older adults' experience of insomnia, as well as areas that have been neglected. The greatest areas of neglect, or gaps in the literature, come from failure to acknowledge the special needs of the older adult population. The Academy of Sleep Medicine recommends in its most recent guidelines that older and younger adults need similar amounts of sleep, but the challenges older adults face make getting that sleep much more difficult. The prospect of increasing dependency, the presence of comorbid

illnesses, and the psychosocial losses associated with aging create environmental press that is not routinely experienced by younger adults or acknowledged by many sleep researchers. Bowling and Lawton and their colleagues have demonstrated the benefits of viewing older adults' quality of life through specially designed "equipment" – namely, a model that takes into account the importance of psychological well-being even in the face of dependency, and instrumentation designed specifically for this population with direct input from older adults. Unfortunately, little has been done on the clinical/insomnia side to adapt instruments or research techniques to capture the broader context and issues behind older adults' insomnia.

A recent in-depth exploration of insomnia literature in health and behavioral sciences over the last 30 years found very few qualitative studies exploring *older adults' own views* about the effects of insomnia on their daily functioning and quality of life. This lack of qualitative study is especially concerning when there is so much evidence that, for older adults, insomnia is frequently triggered or exacerbated by factors like bereavement, recent relocation, institutionalization, polypharmacy or comorbidities that are not explicitly addressed in the instruments and surveys commonly used in insomnia research. Qualitative interviews allow for a more holistic view of the experience of insomnia with multiple, interrelated influencing factors, different contexts and more subjective data, than has been captured in the current literature, which was based on quantitative approaches.

The focus of this dissertation study was a qualitative exploration of the effects of insomnia on older adults' quality of life, which was supplemented with data from traditional, quantitative instruments. By combining methods to study these complex phenomena, this study captured a more complete, holistic and contextualized view of the experience of geriatric insomnia than has been obtained by past efforts using quantitative methods alone. Insomnia has been shown to have far-reaching effects on older adults' functioning and health, and their voices and perceptions need to be included in research aimed at fully understanding the complex interplay between insomnia and quality of life and ultimately at developing possible solutions for this growing population.

Chapter 3: Methods

The purpose of this chapter is to outline the research methodology that was used to describe how older adults at two different points along the trajectory of dependence perceive the effects of insomnia on their quality of life and daily functioning. This chapter describes the qualitative descriptive study design, sample population, and setting, and the procedures for recruitment, data collection, data analysis and protection of human participants.

DESIGN

This study employed a qualitative descriptive approach as described by Sandelowski (Sandelowski, 2000) to elicit the views of older adults residing in two different, and progressively more supportive and restrictive living situations. Qualitative methods, based in Guba and Lincoln's naturalistic paradigm, are well suited to researching this subject because they allow for a more holistic view of the experience of insomnia with multiple, interrelated influencing factors, different contexts and more subjective data, than traditional quantitative approaches (Guba & Lincoln, 1982). The main data source for this study was the semi-structured, face-to-face recorded interviews in which participants described their experiences with insomnia. Interview data were supplemented by widely used quantitative self-report sleep assessment surveys which provided contextual descriptive scores for participants.

SAMPLING

Study Population and Setting

A convenience sample of older adults (age 65 or older) was drawn from residents of the Longhorn Village community in Steiner Ranch, outside Austin, TX. Longhorn Village is a non-profit, continuing care retirement community of over 500 older adults that offers its residents progressively more supportive levels of care. The independent living sector is comprised of villas

within a gated compound or apartments in the main building. The assisted living section is a single building also within the compound containing one-bedroom apartments with 24-hour skilled supervision and assistance. Longhorn Village also includes an access-controlled memory unit, and a skilled nursing facility for long-term care. Many of those in the assisted living and memory unit moved from the community's independent sector as they became more dependent.

In 2016, the most recent year for which data are available, there were 49.2 million older adults in the United States, representing 15.2% or about one in every seven Americans (Administration on Aging, 2018). The Administration on Aging reports that a relatively small number (1.5 million) and percentage (3.1%) of the population aged 65+ live in institutional settings, but noted that the percentage increases dramatically with age, ranging from 1% for persons ages 65-74 to 3% for persons ages 75-84 and 9% for persons age 85 and over (Administration on Aging, 2018). Within the population of people living in some kind of institution, the National Center for Assisted Living reports that there are more than 800,000 Americans residing in assisted living (AL) facilities (National Center For Assisted Living, 2019). Residents of AL facilities usually receive help with some activities of daily living, most commonly bathing, and do not require 24-7 skilled nursing care. More than half of all residents have high blood pressure, and 4 in 10 are living with Alzheimer's disease or other dementias (American Seniors Housing Association, 2017; National Center For Assisted Living, 2019).

Recruitment

Recruitment was divided into two phases: first for residents of independent living section and then for residents of assisted living. For the independent living section, recruitment flyers describing the project, the time commitment and inclusion criteria were distributed in common

areas of the community. Then, at a monthly residents' meeting, the PI gave a talk outlining the context and background of the study and explaining the research questions. The talk was well attended, and many residents expressed interest in participating.

As the study progressed, participants reported their involvement in the project to other residents, several of whom subsequently came forward as volunteers. Informal conversations between the PI and residents about changes in insomnia treatments and attitudes toward sleep resulted in more volunteers, some of whom claimed to have recovered from insomnia and wanted to share their experiences. As data analysis and participant interviewing took place concurrently, it became clear that the stratification between independent and assisted living was more complex than had been planned originally. Some residents of the independent sector were more dependent than had been expected but were able to continue living in the independent sector because they had support from spouses or paid caregivers.

The second phase of recruitment focused on residents from assisted living. The PI had several informal conversations with first the manager of the assisted living section and then the director of healthcare (which included assisted living, the memory unit and the skilled nursing facility) to clarify the aims and requirements of the study and explain the consent procedures. The manager suggested several residents whom she thought might be interested in participating but encouraged contact with anyone. The PI visited the AL section several times and met residents and sometimes family members informally to talk about the study. The PI distributed University of Texas-branded folders containing the IRB approved information letter and recruitment flyer and her business card to residents who expressed interest in participating, and in some cases their family members. Volunteers who met the inclusion criteria were scheduled for meetings.

Inclusion/Exclusion Criteria

To be included in the study, participants had to meet the following criteria:

Inclusion criteria:

- Be age 65 years or older;
- Reside in either the assisted living or independent living sections of the Longhorn Village;
- Be able to speak and understand English;
- Express willingness to participate in the research study and want to speak about the topic.

Exclusion criteria:

There were no additional exclusion criteria.

Sample Size

The primary data source was qualitative interviews therefore, the exact number of research participants was not known until data saturation was complete (Marshall, 1996; Patton, 2002). Data saturation was achieved with 14 participants from independent living and four from assisted living. Quantitative data were collected for descriptive and contextual purposes only, therefore, a power analysis was not performed.

DATA COLLECTION

Institutional Review Board (IRB) approvals for the study were obtained prior to initiating participant recruitment and data collection.

Consent, Privacy and Confidentiality

When individuals expressed interest in participating in the study (via phone or email or in person), the PI reviewed the study purpose, procedures, and time commitment with them and requested their verbal consent to participate. Once verbal consent was obtained, the PI and the

participant set the date and time for the first of two meetings. For assisted living residents, data collection was completed in one meeting.

Residents from both IL an AL at Longhorn Village who agreed to participate were given a unique identification (ID) number. The master list linking the ID numbers and participant names was kept separate from the participant data and will be destroyed at the completion of this study. The quantitative survey responses, audio recordings, transcripts and field notes were all labeled only with each participant's ID number. All of the interviews were led by the PI and were conducted in a quiet, private space usually in the reading room at Longhorn Village or in a quiet corner of the lounge. A few interviews were conducted in residents' apartments. A short pilot phase served to test the recruitment process, interview questions, readability of the surveys, and data analysis procedures. After discussions with faculty, some minor changes were made to survey formats and some additions were made to the semi-structured interview questions. The pilot interviews were included in the data analysis for the whole study.

Procedures

Overall data collection was split into two phases based on living situation, with independent living completed first, followed by assisted living. But with each phase, data collection, and data analysis occurred simultaneously during the study. However, in both groups, once data saturation had been achieved, participant recruitment stopped. Field notes were generated during the interviews directly into digital files using Evernote software and labeled only with the participant's ID number and held in the PI's account, which was password protected. Field notes were supplemented immediately after each interview with additional notes or observations. The raw data from the demographic questionnaires were transcribed into a Microsoft Excel 2018 spreadsheet created and formatted by the PI. Each participant was identified only with his or her record identification numbers. Scores for each of the supplementary instruments were entered on the same master spreadsheet and individual instrument scores were copied to separate tabs for more detailed analysis.

Independent Living – consent and data collection

For independent living residents, three methods were used for collecting data: quantitative instruments, the 7-night sleep diary, and the individual face-to-face interviews using semi-structured open-ended questions. Demographic data were also collected using a demographic questionnaire that was completed at the beginning of the first meeting. In addition, field notes were maintained by the PI throughout each meeting with the participants.

Meeting 1 – Quantitative and CSD

At the first meeting, participants were given an IRB-approved information letter (see Appendices) and allowed time to review the document and ask questions about the study. They were asked to provide a verbal consent to continue in the study, if they wished to continue. Following verbal consent, they completed hard copy forms of the quantitative instruments in the following order:

- Demographic form
- Pittsburgh Sleep Quality Index
- Sleep Hygiene Index
- Insomnia Severity Index
- Geriatric Anxiety Scale
- Dysfunctional Beliefs About Sleep Scale.

The PI introduced each form in turn, explaining what it was trying to measure, and clarifying the response criteria each form requested, for example “during the last month” or “during the last week”. The mood during the meeting was conversational and participants occasionally questioned or commented about specific items or related anecdotes about insomnia or anxiety or other aspects

of their health. Some of the participants expressed some unease about completing the forms so in these cases, the PI read them each of the items and handwrote their responses on the paper forms. All forms were labeled with the participant's ID number only. After the forms were finished, the PI showed them the Consensus Sleep Diary and explained how complete it. Several participants had questions about how to calculate, for example, total time awake during the night if divided into different periods. The meeting concluded by agreeing to a date and time for meeting 2.

Meeting 2 – Diary Discussion and Qualitative Interview

At the second meeting, the PI opened each interview by restating the confidentiality procedures and explaining that she would be taking notes as they talked and that the interview was being recorded. Then she asked the participants to describe their experiences with completing the Consensus Sleep Diary (CSD) and whether it had revealed any new information about their sleep habits. After this discussion she opened the main discussion with the open-ended interview questions, using responses from the diary as a prompt, "So I see from what you've written that you're generally getting 5-6 hours of sleep. Can you tell me about your sleep, and how long it's been like this?" The central interview questions asked, "Tell me about your sleep issues. How would you describe a good night's sleep/bad night's sleep?" The PI asked for additional explanations or clarifications when needed and encouraged participants to express their opinions about their situations with questions such as: "Why do you think that was?" and "How do you feel after a night like that?" The interviews lasted approximately 40-60 minutes.

At the conclusion of the meeting each participant was asked to complete the Mini-Cog cognitive assessment, which consisted of a verbal request to remember three words and then recall them a few minutes later, followed by a written task of drawing a clock on a pre-printed circle.

Assisted Living – Consent and Data Collection

At the preliminary, informal recruitment visits it became clear that most residents of the assisted living section would not be able to complete the same collection of quantitative instruments as people in independent living without considerable stress or inconvenience, and that staff assistance would have been required to complete the CSD. Therefore, for assisted living residents, two methods were used for data collection: a single quantitative instrument (the Pittsburgh Sleep Quality Index) and the face-to-face semi-structured interview. Both were completed at a single meeting, the date and time of which had been agreed at the preliminary informal introduction. All four participants from assisted living asked the PI to read them the PSQI questions, and to avoid repetition, the entire meeting was recorded because many of their insights and opinions came out of discussions around each item on the form, which led logically to the planned semi-structured interview questions. The interviews with assisted living residents were generally shorter, lasting 15-20 minutes. Only three participants from assisted living completed the Mini-cog, because one was unable to hold a pen because of arthritis.

INSTRUMENTS

As a supplement to the qualitative narratives, this study included a demographic sheet, the Pittsburgh Sleep Quality Index (PSQI), the Sleep Hygiene Index (SHI), the Insomnia Severity Index (ISI), the Geriatric Anxiety Scale (GAS), the Dysfunctional Beliefs About Sleep Scale (DBAS), and the Consensus Sleep Diary (see Appendices for copies of these instruments).

The demographic sheet was designed by the PI and contained basic information including age, gender, marital status, ethnicity, level of education, living situation (independent or assisted), and length of time in current living situation. It also asked questions about sleeping arrangements, such as whether the participant had a bed partner, and pets or noisy equipment in the bedroom.

The Pittsburgh Sleep Quality Index (PSQI) is a 19-item, self-report questionnaire that assesses subjective perceptions of sleep quality, latency, duration, efficiency, disturbances, sleep medications, and daytime dysfunction. The 19 items contribute to 7 subscales, each of which has a possible score range of 0-3. Total scale (global) scores range 0-21. Higher scores = more sleep disturbances. Global scores ≥5 is considered indicative of moderate sleep disturbances. Cronbach's alphas from studies with similar populations ranged from .83 to .89 (Buysse et al., 1989).

The Sleep Hygiene Index (SHI) was created to assess behaviors and environmental variables through a 13-item, self-report scale derived from the International Classification of Sleep Disorders (Mastin et al., 2006). Respondents indicate whether each item applies to them using a Likert scale from 0-4 to indicate never, rarely, sometimes, frequently or always. Scores range from 0 to a maximum of 52. Cronbach's alpha (0.66) at development was reinforced by good test-retest reliability (Mastin et al., 2006).

The Insomnia Severity Index (ISI) is a seven-item, self-report questionnaire designed to assess the nature, severity and impact of both nighttime and daytime components of insomnia. The usual recall period is the "last month" and the dimensions evaluated are: severity of sleep onset, sleep maintenance, and early morning awakening problems, sleep dissatisfaction, interference of sleep difficulties with daytime functioning, noticeability of sleep problems by others, and distress caused by the sleep difficulties. A 5-point Likert scale is used to rate each item (e.g., 0 = no problem; 4 = very severe problem), yielding a total score ranging from 0 to 28, with higher scores indicating more severe insomnia (Bastien et al., 2001). Cronbach's alphas from similar adult populations ranged from 0.74 to 0.78. Individual item correlations to the total score ranged from 0.36 (difficulty falling asleep) to 0.67 (interference with daily functioning), with a mean of 0.54. The interpretation of scores are as follows:

- A score between 0-7 suggests that there is no clinically significant insomnia.
- A total score between 8-14 suggests the presence of insomnia symptoms of mild to moderate severity and may warrant discussion with a healthcare professional.

- A score between 15-21 indicates insomnia symptoms of moderate severity which warrant further evaluation and treatment.
- A score between 22-28 suggests severe insomnia associated with significant impairments of daytime functioning and consultation with a healthcare professional is strongly recommended (Morin, n.d.).

The Consensus Sleep Diary is a 15-item, two-page (landscape) standardized form for collecting sleep data for up to 7 days. The form was designed based on patient input and expert consensus and includes questions about sleep and wake times, number of awakenings during the night, time required to fall back asleep after each awakening, caffeine and alcohol intake, and daytime energy levels (Carney et al., 2012).

The Dysfunctional Beliefs About Sleep (DBAS) scale is a 16-item self-rating inventory consisting of statements that evaluate the role of sleep-related beliefs and attitudes in insomnia (e.g., I am worried that I may lose control over my abilities to sleep). Participants indicate their level of agreement with 10-point scales, ranging from 0 (strongly disagree) to 10 (strongly agree). The total score is calculated from the average score of all the items on the scale and could range from 0 to 10, with higher scores indicating higher levels of dysfunctional beliefs about sleep. The developers recommend addressing any items scoring greater than 5 (Morin et al., 1993). The DBAS-16 has adequate internal consistency (Cronbach alpha = 0.77 for clinical and 0.79 for research samples) (Morin, Vallières, & Ivers, 2007).

The Geriatric Anxiety Scale – 10 Item (GAS-10) is a 10-item self-report scale that was designed specifically for use with older adults. It measures anxiety symptom severity in the past week. Responses to the GAS items are made on a four-point, Likert-type scale ranging from 0 to 3. The GAS contains three subscales: cognitive (e.g., difficulty concentrating), affective (afraid of being judged, restlessness) and somatic (e.g., upset stomach, racing heart). Raw scores of 1-6 indicate minimal anxiety; scores from 7 to 10 indicate mild or moderate anxiety, and scores from 12 to 30 indicate severe anxiety. Internal consistency for GAS has ranged from alphas of 0.9-0.93 in similar populations (Segal et al., 2010).

The Mini-Cog test is a 3-minute instrument to screen for cognitive impairment in older adults in the primary care setting. The Mini-Cog uses a three-item recall test for memory and a simply scored clock-drawing test. Participants are first given three words, asked to repeat them, and told that they will be asked to recall the words in a few minutes. Participants are then given a paper printed with a large circle and asked to draw a clock face, putting all the numbers in where they go. Then they are asked to set the hands of the clock showing 10 minutes past 11. Developers noted that the latter serves as an "informative distractor," helping to clarify scores when the memory recall score is intermediate.

To score the Mini-Cog, one point is given for each word recalled without cueing, and two points given for a normal clock, for a total of five. To earn the full two points, the clock must have all numbers placed in the correct sequence and approximately correct position (e.g., 12, 3, 6 and 9 are in anchor positions) with no missing or duplicate numbers. Hands are pointing to the 11 and 2 (11:10). A score of <3 on the Mini-Cog has been validated for dementia screening, but many individuals with clinically meaningful cognitive impairment will score higher. When greater sensitivity is desired, a cut point of <4 is recommended as it may indicate a need for further evaluation of cognitive status. (Borson, Scanlan, Brush, Vitaliano, & Dokmak, 2000). The Mini-Cog is less affected by subject ethnicity, language, and education, than the Mini Mental State Examination and can detect a variety of different dementias. Moreover, the Mini-Cog detects many people with mild cognitive impairment (cognitive impairment too mild to meet diagnostic criteria for dementia) (Borson et al., 2000; Dorflinger, 2015)

DATA ANALYSIS

The participants' transcripts were analyzed using conventional content analysis as described by Hsieh and Shannon (Hsieh & Shannon, 2005). Hsieh and Shannon recommend using conventional content analysis when existing theory or research literature about a phenomenon is limited, and stress that its advantage is gaining direct information from study participants "without imposing preconceived categories or theoretical perspectives" (Hsieh & Shannon, 2005, p. 1279).

Interview Transcriptions

The digital audio files of the interviews, labeled with the ID number of the participants, were professionally transcribed into typed text by GMR Transcription. The files were transcribed verbatim, with words spelled as they were spoken to include mispronunciations and time stamps were marked every 60 seconds. Additionally, incomplete sentences, or noises heard during the interview were reflected as such in the typed text. The typed transcriptions, also labeled with the ID number, were saved in Microsoft Word .docx format.

Coding

The PI read each transcript several times to become familiar with the content. Coding was performed by hand with highlighter and different colored pens. In the initial coding, significant quotations and expressed opinions were highlighted and concepts mentioned or indicated by the participant were noted in the margin. Examples included "reduced energy"; "Rx melatonin" "coping mechanism?" Key concepts or unusual experiences for the participant were listed on the top of the first page of the transcript for quick reference. In subsequent coding passes, significant quotations were again flagged and annotated, and each sentence or response was coded as recommended by Saldaña, sometimes with a basic restatement of the response (Saldana, 2013).

To synthesize the interview data and develop categories, each transcript was reviewed again, and the coded meaning units were typed into an Evernote document. Each time a meaning unit or concept appeared again in another transcript, the ID number of that participant was typed next to the concept or meaning unit, providing a rough frequency count of the most common experiences, comments and perceptions. Related concepts and repeated quotations were grouped together, and the most frequently used concepts or ideas were examined for possible development as categories. Saldaña's guidelines for assessing "quantities of qualities" during coding and synthesis provided a base for determining themes and categories (Saldana, 2013, p. 25).

Trustworthiness

Trustworthiness and rigor of the results was assured by employing Guba and Lincoln's recommended criteria of credibility, transferability, dependability and confirmability (Guba & Lincoln, 1982). Credibility was achieved through debriefing with faculty to discuss possible themes and categories, and by following the content analysis methods described. A thorough audit trail of meetings, field notes and synthesis notes helped to ensure dependability.

In addition, a member check meeting was held toward the end of data analysis to ensure confirmability and transferability. The PI prepared a three-page summary of results, including the overriding theme and three major categories with supporting quotes, and met at Longhorn Village for 45 minutes with four participants from the independent living section to discuss the results. The participants recognized pieces of their own experiences and agreed with the analysis overall. One participant reported that he personally did not experience one of the three major categories but recognized that other people did.

Quantitative Data Analysis

Each of the quantitative questionnaires was scored by hand according to the developers' criteria and the totals marked on the hard copies. Scores for each instrument were entered onto an Excel spreadsheet and analyzed for basic descriptive statistics. Participants were listed on the spreadsheet only by their ID number, but it was possible to compare quantitative and qualitative responses to similar questions.

PROTECTION OF HUMAN PARTICIPANTS

Risks to the Participants

There were no anticipated risks for participants in this study that are beyond those that would be experienced in their everyday life. However, it was possible that participants could experience some emotional distress while they are describing reasons for their insomnia (e.g. death

of a loved one). No distress was observed or communicated during interactions with the participants in this study.

Potential Benefits of the Study

There were no direct benefits to the participants in this study. However, knowledge gained from this project supported a greater understanding of the sleep habits, knowledge of sleep hygiene, and thoughts and beliefs of older adults of the relationships between sleep quality and daily functioning, and quality of life.

SUMMARY

In summary, this study addressed gaps in the literature by eliciting the views of groups of older adults in two progressively more restrictive living situations -- independent living, and assisted living (distinct stages on the trajectory of dependence). Residents' perceptions of insomnia, its effects on their daily functioning and quality of life, and the ways their experience of insomnia has changed as they aged and became more dependent were recorded. By including older adults at increasing levels of dependency, this study has provided some insights into the role that insomnia plays in the day-to-day lives of older adults and may provide support for how insomnia interventions can be designed for older adults across dependency levels.

Chapter 4: Results

This chapter presents the results of this dissertation study. The first section presents the demographic characteristics of the sample (N=18). The next section reports the descriptive quantitative findings by each instrument. The third section describes the findings related to the theme, the categories, and subcategories revealed in the participants' narratives. The purpose of this qualitative descriptive research was to explore the effects of insomnia on quality of life and daily functioning as perceived by older adults. The study included interviews with 18 older adults living at two different points on the trajectory of dependence. The design and methods used were consistent with Sandelowski's descriptions of the qualitative descriptive methods (Sandelowski, 2000). Participant recruitment, interviews, and data analysis were completed concurrently. The analyses of the interview data led to the emergence of themes, sub-themes, and categories, and data collection concluded when the point of saturation was achieved. The 18 older adults in this study voluntarily shared their honest thoughts and reflections about their insomnia and its effects on their quality of life and daily functioning. To protect the identities of the participants, the comments are labeled with the living situation of each participant (IL= independent living; AL= assisted living) and his or her ID number. Any names mentioned in comments were removed.

DEMOGRAPHICS OF THE SAMPLE

Study participants were men and women age 65+ living in either the independent or assisted living sections of a large up-scale retirement community located in the Central Texas area. The participants consisted of 12 women and 6 men, with an age range from 67 to 96 years, and a mean age of 84 years. Fourteen of the participants resided in the independent living sector, either in villas within the gated compound or apartments in the main building, and four lived in the assisted living section, in one-bedroom apartments with 24-hour skilled supervision and assistance. The participants had lived in the community for an average of 6.47 years. Seven participants were able to walk independently, eight used a walker, and two used a wheelchair. All of the participants

were Caucasian and educated: five had bachelor's degrees; an additional seven had graduate degrees. Participant characteristics are summarized in Table 1 below.

Participant Characteristics		***n***
Gender n (%)	Female	12 (66%)
	Male	6 (33%)
Race/ethnicity n (%)	White/Caucasian	18(100)
	Other races	0 (0)
Marital Status n (%)	Single	1 (5%)
	Married	10 (55%)
	Widowed	5 (28%)
	Widowed with new partner	2 (11%)
Age Mean (SD)	Years	84.0 (7.62)
Education n (%)	High school only	0
	Some college	4 (22%)
	Associate degree	2 (11%)
	Baccalaureate degree	5 (27%)
	Graduate/post-graduate	7 (38%)
Living Situation n (%)	Independent	14 (78%)
	Assisted	4 (22%)
Mean time in current living situation n (SD)	Years	7 (3.15)

Table 1: Participant Characteristics

The Mini-Cog

The Mini-Cog test was administered to all participants to provide a basic screening for cognitive impairment without stigmatizing any individuals. The Mini-Cog consists of a three-item recall test for memory and a simply scored clock-drawing test. To score the Mini-Cog, one point is given for each word recalled without cueing (maximum three points) and two points given for a normal clock, for a total of five. A score of <3 on the Mini-Cog has been validated for dementia screening, but many individuals with clinically meaningful cognitive impairment will score higher (Borson et al., 2000). Although most of them were living independently, fewer than half of the

individuals were able to remember all three words and draw an analogue clock showing the requested time, both of which are required for a normal score.

QUANTITATIVE SLEEP & ANXIETY MEASURES

The independent living participants completed four standard self-report sleep surveys, and a 7-night Consensus Sleep Diary before meeting with the PI for the qualitative interview. The assisted living residents completed one self-report sleep instrument, the Pittsburgh Sleep Quality Index, and the qualitative interview. All of the sleep assessment surveys are designed for the general adult population, rather than specifically for older adults. These quantitative assessments were included in order to provide standard contextual information to supplement the data elicited through the qualitative interviews. The key descriptive results of these self-report instruments are summarized in Table 2 below and described in more detail in the following paragraphs. The numbers of respondents in the results differ due to participant willingness to complete some of the instruments.

Variable	Score
Bedroom environment	N (%)
None	11 (60%)
Bed partner	5 (28%)
Pets	0
Noisy equipment	0
Partner + pets	1 (5%)
Partner + equipment	1 (5%)
Pets + equipment	0
All three	0
PSQI (N=18)	**Mean (SD)**
Global score (>5=sleep problem)	9.11 (3.83)
Duration – hours	6.5 (1.38)
Daytime disfunction (scores 0-3)	0.78 (0.73)
Medication use (scores 0-3)	1.67 (1.38)
Sleep quality (scores 0-3)	1.38 (0.7)
Sleep onset latency (minutes) recommended 5-15)	32.9 (31.5) Median = 25
Sleep efficiency (percent)	77 (13) Median = 79
ISI total (N=10) Possible range 0-28	10.4 (5.36) Median = 9
SHI total (N=16) Possible range 0-52	12.13 (5.28) Median=11
GAS total (N=10) Possible range 0=30	4.4 (1.96)
DBAS total (N=10) Possible range 0-10 (items >5= dysfunctional beliefs)	4.29 (1.42)

Table 2. Quantitative Sleep Survey Results

The Pittsburgh Sleep Quality Index

The Pittsburgh Sleep Quality Index (PSQI) is a 19-item, self-report questionnaire that assesses subjective perceptions of sleep quality, latency (time to fall asleep), duration, efficiency (time spent in bed vs. time actually asleep), disturbances, sleep medications, and daytime dysfunction. The PSQI asks respondents to check boxes indicating the frequency of 13 different

sleep-related events, such as getting up to go to the bathroom or feeling too hot or too cold in bed. For each event, the options on the form are: not during the past month (scores 0); less than once a week (scores 1); once or twice a week (scores 2); or three or more times per week (scores 3). Total (global) scores range from 0-21 and higher scores indicate poorer sleep.

All 18 participants completed the PSQI and the mean score was 9.11 (scores >5 indicate significant sleep problems), with a range from 4 to 15. Five participants had total scores of 14, and one scored 15. The highest scoring items -- that is, events that the most people experienced three or more times per week – came from questions about sleep medication use, long sleep latency, short sleep duration, and multiple awakenings. Participants reported an average sleep latency of 33 minutes, longer than the recommended five to 15 minutes (Sateia et al., 2017), but four participants reported experiencing sleep latency of more than an hour several times a week.

The six participants with the highest PSQI scores reported some common experiences. All of the participants scoring 14 and higher resided in the independent living sector. Three of the six reported that it took them more than an hour to fall asleep each night. All six got up multiple times in the night to urinate. Additionally, bereavement seemed to be a common precipitating event for insomnia because three of the highest scoring participants explicitly stated that loss of their spouse/partner was a precipitating factor in their insomnia. One person said:

> I have not slept well since the day {name of husband} died. I wake up all night…I was always used to having somebody in bed with me or being so tired I couldn't stay up any longer. And it really affects what I do in the daytime (IL18, line 14 & 41).

A fifth high-scoring participant noted that her insomnia had started when her son committed suicide in mid-life, about 12 years earlier.

There were some descriptive differences between the independent living residents and the assisted living residents on the PSQI. All four of the study participants from the assisted living side of the community reported much earlier bed times than the IL residents on the PSQI – generally between 8 and 9pm – and said that they did not choose their sleep schedules but had to go to bed when the staff came to get them ready. All four participants were able to transfer

independently to the toilet with a walker, and toileted themselves during the night. But they were required to go to bed when the staff came around for the evening medications pass. Separating PSQI scores by living situation, the four assisted living residents reported more daytime sleepiness, more pain, and greater sleep medication use that the independent living residents. But their use of sleep medications may have also resulted in their experience of shorter sleep latency and longer sleep duration than the independent living (IL) participants. The mean PSQI scores for the AL residents were 5.75, lower than those for the 14 IL residents at 10.07, indicating that they generally had better sleep. In addition to global sleep quality, IL participants also completed the Insomnia Severity Index to provide a specific insomnia score.

The Insomnia Severity Index

The Insomnia Severity Index (ISI) is a seven-item, self-report questionnaire is designed to assess the nature, severity and impact of both nighttime and daytime components of insomnia. The independent living residents completed the ISI, in addition to the PSQI. The mean score for this study (N=10) was 10.4, with scores ranging from 4 to 19. According to the ISI scoring guidelines, scores from 0-7 suggest no clinically significant insomnia; 8-14 suggest the presence of insomnia symptoms of mild to moderate severity. The scoring guidelines state: "Although this degree of insomnia severity may not require immediate treatment, you may still want to talk to a health-care professional about your sleep (for further evaluation) or continue monitoring these symptoms to check if they worsen over time." (Morin, n.d., p. 2). However, two participants scored 19, which according to the scoring manual indicates moderately severe insomnia "with symptoms significant enough to warrant further treatment" and a medical consultation is strongly recommended (Morin, n.d., p. 2). The ISI items that participants rated as most troublesome were item 4, ("how satisfied are you with your current sleep pattern?") and item 2 ("how do you rate your difficulty staying asleep"). The two participants with the highest scores on the ISI were again widowed individuals who had cited their spouses' deaths as the trigger for their insomnia. Both reported being "very dissatisfied" with their current sleep pattern and having "severe" difficulty staying asleep. One

participant stated: “It [bad sleep pattern] just really messes my whole day – I just don’t wanna do anything…just sit in a chair” (IL18, line 104).

The Sleep Hygiene Index

The Sleep Hygiene Index was created to assess behaviors and environmental variables through a 13-item, self-report scale derived from the International Classification of Sleep Disorders (Mastin et al., 2006). Scores range from 0 to 52, with higher scores indicating poorer sleep hygiene. The average SHI score in the participants who completed this instrument (N=16) was 12.13, and the highest scoring item (most problems) was “I think, plan or worry while I am in bed.” As indicated by the relatively low mean score, most of the participants in this study were fairly knowledgeable about best practices in sleep hygiene.

The Geriatric Anxiety Scale and The Dysfunctional Beliefs About Sleep Scale

Anxiety is a common perpetuating factor in insomnia and is frequently underdiagnosed in older adults. The Geriatric Anxiety Scale 10-item (GAS-10) was included in the survey packet to assess participants’ general anxiety levels as a possible contributor to insomnia. It measures anxiety symptom severity in the past week, and responses to statements such as “I felt tired” or “I felt I could not control my worry” are made on a four-point, Likert scale ranging from 0 (not at all) to 3 (all the time). The responses are summed to create a total score, to a maximum of 30, with higher scores indicating greater anxiety levels (Gould et al., 2018; Segal et al., 2010).

In this study, the mean total score on the GAS-10 was 4.4, with responses ranging from 1 to 8. Item 7 on the GAS-10 (“I felt tired”) had the highest response with a mean of 1.2, followed by item 5 (“I could not control my worry”) with a mean score of 0.7. Scoring instructions for the GAS-10 suggest that responses of 4-8 indicate minimal or mild anxiety, and only scores above 10 indicate severe anxiety. However, many participants who marked low scores overall on the GAS form, later recounted anxious situations and fears in the interviews, particularly when describing

why they felt they could not sleep. This discrepancy is illustrated by participant IL4 who scored a 3 on the GAS but described her frustration and anger about her sleep issues as follows:

> Well, I mean I just have some anxiety about going to bed because I don't ever know. Although sometimes I know because I try to do something calming before I go to bed like sit in my chair and read and sometimes I'll start to get the restless leg then and so I'll know I'm gonna have it [a Bad Night] (IL4, line 169).

The Dysfunctional Beliefs About Sleep scale (DBAS) was included in the study to provide a description of anxiety directed specifically at the experience of poor sleep and insomnia. Participants indicate their level of agreement with statements that evaluate the role of sleep-related beliefs and attitudes in insomnia (e.g., "I am worried that I may lose control over my abilities to sleep") on 10-point scales, ranging from 0 (strongly disagree) to 10 (strongly agree). The total score is calculated from the average score of all the items on the scale and ranges from 0 to 10, with higher scores indicating higher levels of dysfunctional beliefs about sleep. (Morin et al., 1993, 2007). The mean score for the sample was 4.29. According to the DBAS scoring guidelines, those with total scores of 4 or greater, or those with high rating on an individual item (i.e., 6 or greater) may have unrealistic expectations for sleep, or their thoughts about their sleep or their ability to cope with sleep loss have become a factor in their sleep problem (Morin et al., 1993, 2007). The four highest scoring items (all at or above 6, indicating beliefs may be negatively affecting sleep) are laid out in the chart below.

DBAS Item	Mean Item Score (0-10)	Number of participants selecting "strongly agree" (N=10)
I can't ever predict whether I will have a good or poor night's sleep	8.3	8
I need 8 hours of sleep to feel refreshed and function well during the day.	6.9	5
When I feel tired, have no energy, or just seem not to function well during the day, it is generally because I did not sleep well the night before.	6.5	2
I am concerned that chronic insomnia may have serious consequences for my physical health.	5.9	3

Table 3. DBAS Item Results

The unpredictability of insomnia and lack of control over it was a source of great frustration to many participants. However, there was little overlap between the high scores on the GAS and the high scores on the DBAS. Participants who reported high levels of anxiety about their sleep on the DBAS, did not report high levels of general anxiety on the GAS. For example, participant IL4, reported little anxiety on the GAS-10 as described above, but articulated her anger and frustration about her insomnia in the interview, and scored a 5.44 on the DBAS, well above the mean. Many participants described their 'race car brains" or churning minds, or ruminating

behaviors at night in the interviews but did not report a high score on "I cannot control my worry" on the GAS-10. One participant related there experience this way:

> The mind is just churning away. So, I sometimes have to try to say to myself, "Stop thinking." If I go to sleep right away, then sometimes two hours later I'll wake up and then I can't get back to sleep again for one, two or three hours and again [it's] the same process of the mind incessantly thinking of one thing and another (IL13, line 14).

The Consensus Sleep Diary

The Consensus Sleep Diary is a 15-item, two-page (landscape) standardized form for collecting sleep data for up to 7 days. The form was based on patient input and expert consensus (Carney et al., 2012). Participants from independent living completed the diary for 7 nights before meeting the PI for the qualitative interview, and several reported that they found the exercise of recording their sleep habits and particularly the number and length of awakenings useful. One participant related the experience of completing the diary as follows:

> Oh, I knew that I was doing poorly with my sleeping. But this sure proved it. It really proved it. I need more sleep than I'm getting. Now the time I got eight, I don't know what happened that night except I think I probably couldn't go to sleep or woke up in the middle of the night. And then when I went to sleep, I just slept on 'till 10:30, I think, in the morning (IL20, line 29).

These quantitative measures provided useful contextual information regarding the state of insomnia symptoms experienced by these participants. However, as has been illustrated by the narrative comments, there were gaps in the experiences that were not adequately captured by these standard quantitative measures. The next section will describe the results from the qualitative interviews conducted with all participants.

QUALITATIVE RESULTS

Overall theme and categories

The older adults in this study were asked to describe the effects insomnia had on their quality of life and on their daily functioning. Conventional content analysis of the 18 interviews

exposed the overall theme: Insomnia Is Exhausting. This overall theme of Insomnia Is Exhausting is composed of four categories that describe and explain the theme: A Bad Night, Self-Management, Stoicism, and Consequences (see Figure 7). The category of A Bad Night contained two sub-categories: Loneliness and Anxiety. The category of Self-Management contained four sub-categories: Exercise, Diet, Routine, and Medication. The category of Stoicism contained one sub-category: Stigma. These categories are closely linked and interact to explain the overall theme, Insomnia Is Exhausting. A large portion of all the narratives fit into the category of A Bad Night, and the experiences of A Bad Night were strongly linked to Self-Management and Stoicism. These three categories intersected and together created the fourth category of Consequences.

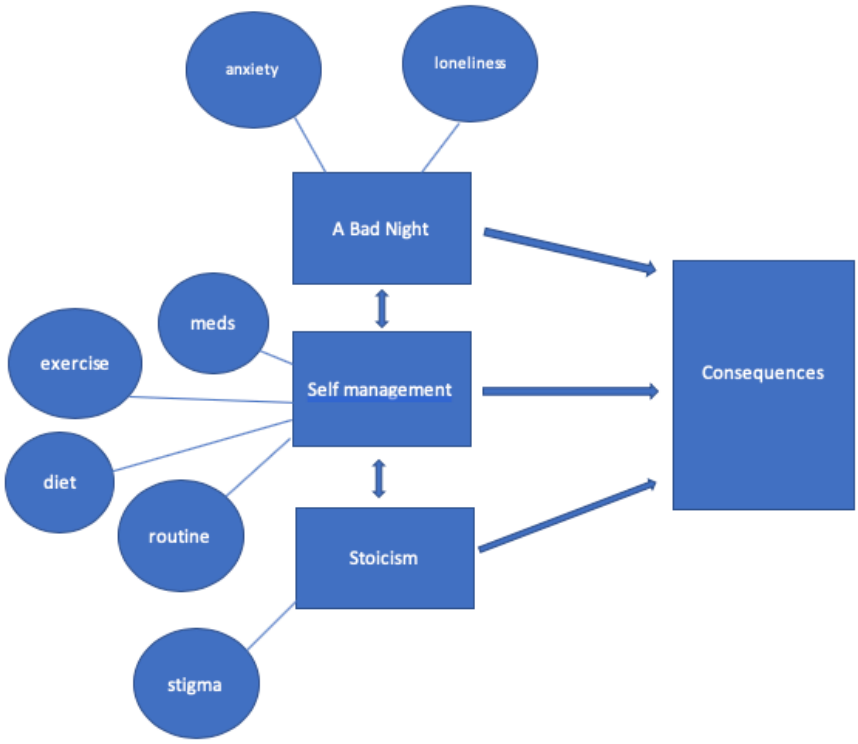


Figure 7. Insomnia Is Exhausting.

The overall theme of Insomnia is Exhausting describes the participants' reports that their sleep difficulties exhausted them, not only because many of them were chronically sleep deprived but also because they devoted much physical and mental energy toward managing or controlling/limiting the effects their insomnia on their daily functioning. They also found the strain of worrying about their insomnia to be mentally and emotionally exhausting. Insomnia is Exhausting is composed of four categories: Bad Night, Self-management, Stoicism, Consequences. Each category and their corresponding sub-categories are described below. Illustrative narrative participant quotes are provided for each.

A Bad Night

The experience of A Bad Night was mentioned by nearly every participant in this study. The definition of A Bad Night varied from person to person. For many of the older adults in this study, A Bad Night meant getting four or five hours of sleep or less, often attained only after lying awake, perhaps for an hour or more. If they were lucky and eventually fell asleep, many of participants described how they would wake up two or three, or in the worst case, six times over the next few hours, often to go to the bathroom, but sometimes for no obvious reason. For those with sleep latency issues, each awakening often required another frustrating period of trying to get back to sleep – sometimes 15-30 minutes or more for each awakening. For other participants, the Bad Night followed a different pattern: falling asleep fairly easily but waking up in the early hours and then lying in bed, unable to sleep, waiting for morning. The frequency of Bad Nights varied. Some participants reported having two to three Bad Nights a week; others had only two or three per month. A few participants met the general criteria for Bad Nights every night, sleeping a maximum of five hours and waking at 4am every day, unable to sleep any later.

Two important sub-categories that described emotional reactions to A Bad Night came up repeatedly in interviews: Loneliness, and Anxiety. These sub-categories are further described next.

Loneliness

Insomnia is an isolating condition. Lying awake when the rest of the world is asleep is lonely and frustrating and the emotional aspects frequently exacerbate the resulting sleep deprivation. One participant described the experience this way: "If you're still awake at 3 or 4am, that's a bad night and it gets really scary. You think, 'Am I gonna be awake all night?' I've had that feeling" (IL10, line 128). While another said: "There are times when I do not close my eyes all night long" (IL18, line 62). The loneliness of sleeping without a beloved spouse after a long marriage was reported by six of the seven of the participants who were widowed and three of these specifically noted that the death of their spouse precipitated their insomnia. One participant said:

> This [insomnia] has all come about since – I can't pinpoint the month but – since my wife died. She died, it'll be three years in November. She died here, and she was the only love of my life. We were married 57 years…I'm not over it, but I could cry just at the mention of her name (IL7, line 44).

A woman described her strategies to avoid being awake alone in the bed she used to share with her husband.

> I got into the habit of going to bed in the middle of the -- 12:00 or 1:00. Because after he died, if I went to bed earlier than that, I would wake up at 2:00 or 3:00 and be awake for a couple of hours (IL20, line 346).

Anxiety

Anxiety was the second strong emotion mentioned repeatedly in reflections about A Bad Night. Participants' descriptions of anxiety took different forms. Some participants worried about the effects on their long-term health. One participant related the following internal discussion:

> If I don't go to sleep, and I get up and move around, and then it's, oh, 3:00, 3:30, 4am. And I think I'm not gonna get enough sleep because you hear of all the bad things that go on in your head when you don't get enough sleep. It leads to Alzheimer's, and I don't know what else, cancer, anything. You name it (IL10, line 77).

Others admitted that worrying about work problems at night had been a habit before they retired, and although the work-related stresses were removed, the habit remained.

> "My sleep pattern has been affected by an involvement in work, or a lack of involvement in work… I became head of *** here in Austin, which was stressful, so I had a lot of sleep problems during that time. And I found that I was very tense and couldn't go to sleep for obvious reasons (IL12, line 15).

But for many participants, anxiety itself was one of the key things keeping them awake.

> I would lay and I'd toss and turn all night and getting totally comfortable, or feel comfortable. And I would have stuff going in my head, worrying this or redoing that or whatever the stuff was. And I struggled with that. I mean, I would often lay there, hour, hour and a half, even two hours, with all that and not being able to sleep. Or then if I did sleep, I would wake up during the night for big stretches, maybe an hour, hour and a half (IL3, line 59).

> It [insomnia] worries me. I get panicky at night and I thought, "Why am I laying here. I just can't sleep." You always read if you can't sleep I mean yeah you read if you cannot sleep in bed, get up and read a book. So, I get up and do the crossword puzzle or a jigsaw puzzle (IL10, line 388).

One AL resident described in emotional detail the incapacitating anxiety and deep depression she had experienced over the last year in which, like Irene in the case study at the beginning of Chapter 1, she experienced multiple precipitating events in a short space of time. Her husband had been diagnosed with dementia, they sold their beloved home in Houston and moved to Austin to be near their daughter, but the move made her husband even more disoriented and eventually he moved into a memory unit. "The whole move was traumatic… I had too many decisions… after a while I really didn't want to live" (AL25, line 423). Her insomnia and paralyzing anxiety were eventually controlled with medication after she had moved to assisted living but the trauma of the experience and its effects on her family stayed with her. Many of the participants described A Bad Night not only as a lonely and anxious experience to live through, but also as a perceived threat, an event they dreaded and worked to avoid. Their efforts to contain or self-manage this threat make up the second category under Insomnia is Exhausting.

Self-Management

Chronic insomnia had left many of the participants permanently sleep deprived. It affected their mood and cognition and was a regular source of stress. They spoke at length about the continual efforts they employed to self-manage their insomnia and to recover from or compensate

for A Bad Night when one occurred. Although many of the participants tried to control their insomnia with exercise, diet restrictions, medication use, and strict routines (typical sleep hygiene recommendations), they recognized that much of the time, their efforts had little effect or were easily derailed. These efforts form the four sub-categories under Self-Management and are explained below.

Exercise

The retirement community was very well equipped with a gym and indoor pool and offered different exercise classes throughout the week. Most of the participants mentioned attending exercise classes or doing their own exercise regimes "to get tired". "I usually walk a mile or a mile and a half in the morning, right after I get up. And that helps. And I work out in the weight room as well" (IL12, line 119). Another woman described her exercise efforts as compensations for poor sleep.

> I exercise in an attempt to get tired enough to sleep readily, but the problem is now with my leg problem; the exercises that the doctor gave me are not really very strenuous. Like yesterday, I was in the pool for about an hour, but it seems a lot more like floating around than it does building up a sweat (IL15, line 81).

Diet

Caffeine and alcohol intake were assessed on the Sleep Hygiene Index and the Consensus Sleep Diary that the independent living residents completed. Many closely monitored their intake of caffeine or in many cases cut it out completely due to their understanding of the alerting effects of caffeine. One participant stated:

> It [caffeine] is a problem for me. I can't drink iced tea in the evening, for example. I can drink decaf… and colas and things like that, I can't do anything like that after 3pm (IL12, line 174).

Medication

Participants reported conflicting attitudes towards use of sleep medication. Almost all had either tried some pharmacological remedies in the past or were taking some at the time of the interviews. Two participants who claimed their insomnia had been "cured" stated that medication had been the solution. One claimed melatonin had made a huge improvement (IL3, line 78) and the other said her life had been transformed by daily mirtazapine and PRN Ambien (IL9, line 11). Melatonin, the hormone secreted by the pineal gland that helps control the daily sleep-wake cycle, is available over the counter and many participants were taking it at the time of the interviews, or had taken it in the past, but only one person definitely felt it had helped improved his sleep. Other Melatonin users expressed skepticism about its beneficial effects and two openly suggested it was just a placebo. "I think maybe it [melatonin] helps me more psychologically because I think, 'I've taken it. I'm going to go to sleep'" (IL10, Line 209). A few of the participants who had been living with insomnia for many years expressed skepticism about medication, claiming it did not help their condition, even as they bewailed their exhaustion.

> If I take melatonin, I'm awake all night long. It does not help me. I've taken up to 10 melatonin trying to get – none of it. I'm just awake on it. That doesn't help. And if I feel really badly or have a pain or something, I might take a Tylenol PM. Puts me right to sleep. And in about three or four hours, I'm awake the rest of the night. It doesn't last very long. And I don't think I've ever tried anything else. Yeah, I did do – after a time that the doctors had – I could not sleep. And he said, "Take an Adrenalin [Ambien]" I took it three nights in a row and stayed awake the entire night all three nights. It didn't help any (IL18, line 110).

Several participants hypothesized that prescribed medications had actually caused their insomnia, (IL4, line 62; IL10, line 39). Others stated adamantly that not taking medication was part of their efforts to manage their insomnia. An 82-year-old woman explained her refusal to take medications.

> I've never taken medication for it [insomnia]. And I know people say Ambien and all kinds of other things. And I have just not done that. I don't think that's healthy sleep. And I have tried relaxation responses and meditation and also following all the rules. "Be in a dark room for a while. Don't be out in the light. Avoid looking at a blue screen if you can." … But things don't really seem to work very well (IL12, line 53).

Strict Routines

Many participants stressed their efforts to get up at their regular time (i.e., not sleeping late) even after a Bad Night, even after four hours or less of sleep. One participant described her strict routine this way:

> Oh, no, no. Even then I don't sleep in. Like my husband sleeps in if he doesn't sleep well. He sleeps in. I don't ever do that. I keep a strict going to bed and waking up… I just feel that's what works and I'm just afraid it'll get the whole cycle off if I, – So, no. I don't [sleep late] after anything" (IL4, line25).

The strict routines of many of the participants from independent living section contrasted sharply with the observations of the four participants from the assisted living section, who recounted the loss of control over their sleep schedules that they had experienced since moving into AL. Even though all four participants from AL were able to transfer independently with a walker, they were required to go to bed when the staff came around for the evening medications pass. They accepted this regime with equanimity and were outwardly grateful for the assistance. One participant described it this way: "I have to be in bed by about 8:00 to 8:20 for medicines and to relieve the caregiver because she's got – the CNA here has this whole wing" (AL24, line 60). While another participant, a 91-year old man with mild cognitive impairment, explained that he was still able to watch TV once he was in bed, "but I've had a full day, it's only a little while and then…" and he laughed and mimed falling asleep (AL23, line 63).

When asked about their sleep habits before moving to assisted living, the AL participants generally described greater flexibility and a more varied routine. But in describing their past routines, they also reported increasingly complicated domestic arrangements as they became more dependent, and experienced increasing anxieties over their declining health. Sleep quality was a minor issue for these individuals in the face of crises like falls, selling the family home, and navigating different residential care options.

Stoicism

Stoicism was another category that encompassed many participants views about insomnia and its effects on their quality of life. Stoicism, defined as the endurance of pain or hardship without display of feelings and without complaint ("Stoicism," 1968), appeared in multiple narratives as participants described how they were determined not to give in to their exhaustion. Participants expressed pride in their attempts to carry on as normal even after very little sleep, for example, by adhering to their exercise classes or walking regimens. An 80-year-old woman who had been living on less than five hours of sleep for many years reported that she woke up every day between 3:30 and 4am, regardless of the time she went to bed. She laughed as she described how she was known for being the first person to sign out at reception every morning, when she went out to do her exercise around 4:15am. She wore a Fitbit and regularly walked one to one and a half miles every day on the footpaths around the complex (IL6, line 84). Another participant, with the highest PSQI score (15/21) in the study, described her efforts to dress well even after a night with only a few hours' sleep.

> I think you should look as best as you can when you live in a place like this. Some people just don't care. I think, "Bless their old hearts. That's so pitiful." Even I don't look all that good. But I at least try to be clean and have makeup on and clean clothes and have my hair combed every day (IL18, line 134).

Despite the up-scale nature of this retirement community, it became clear in the narratives that some participants had grown up in poor families. Several participants brought up the fact that they had grown up on a farm and had been expected to get up early. For participants with these past experiences, not sleeping well was more of a nuisance than a chronic condition. This 80-year-old woman took 4 different sedating medications every night and still only slept four or five hours.

> I mean, these people that sleep until 10:00, I don't know how they handle it. I mean I have never in my whole life slept until 10:00 even when I was a kid and everything because I lived on a farm and we got up early and went out the field and stuff you know. So there's no way I could have slept (IL6, line 206).

Stigma

The stoicism was especially apparent in stigma participants associated with daytime napping. Five participants emphatically stated that they did not nap, and denied napping on the quantitative measures, but then admitted in interview that they dozed off during the day in front of the television or after a meal. Statements like "I know you're not supposed to [nap] but..." reflected the stigma associated with this coping mechanism for sleep loss and a fear that napping was perpetuating their insomnia. An excerpt from one transcript demonstrates the stigma associated with napping.

Interviewer: Do you nap during the day?

Interviewee: No. Occasionally, I'll fall asleep watching television or something.

Interviewer: Is that in the evening or during the day do you think?

Interviewee: That's during the afternoon. It's about an hour. That helps a little bit (IL7, line 33).

And another participant tried to downplay her napping.

Interviewee: My legs hurt me, so I don't walk around a lot. I do a lot of sitting and then I get sleepy, doze off. I don't make a habit of it.

Interviewer: So, napping in the afternoon, how often do you think you do that?

Interviewee: Oh, maybe once a week at the most. It's not often because I know you shouldn't sleep during the day. You're not gonna sleep at night (IL10, line 108).

Many of them drew firm distinctions between napping, which generally implied deliberately going to bed during the day and was viewed by many as a sign of weakness, and nodding off in front of the television, which was an acceptable coping mechanism.

Interviewee: I feel tired and irritable and don't have much energy. I don't take naps.

Interviewer: That's one of my other questions.

Interviewee: Sometimes when I'm reading or something and I'll get sleepy and it'll be hard to keep awake, but usually I don't have that. Well, not normally unless I have trouble sleeping (IL5, line 135)

Moments later he carefully clarified his actions: "I don't care for the term nap. The way I think of napping is actually going to sleep. No, I'll be reading something and I'll kind of start to nod off" (IL5, line 148). The participant who walked every morning around 4am admitted to having a 10-minute nap in a chair after exercising, but denied having any regular daytime sleep (IL6, line 520). Despite the participants' determined efforts to self-manage or control the effects of their insomnia, many reported negative effects on their daily functioning and quality of life. These Consequences make up the fourth category under Insomnia Is Exhausting and are described next.

Consequences

Chronic insomnia has direct and indirect negative effects on participants' daily functioning and quality of life. Direct effects include reduced energy and stamina, poor mood, and reduced functional capacity. The indirect effects include reduced social interaction and increased isolation as participants try to compensate for their exhaustion or reduce their social activities in hopes of improving their sleep.

Participants recounted multiple examples of their reduced daily physical and cognitive functioning after getting less than five hours of sleep. One participant who regularly slept for only five hours said her husband described her as grouchy, and said she felt sluggish.

> Well what I say is I can do manual labor, but I can't do brainwork, if that makes sense… I mean I don't do stuff with my checkbook or I don't do things that really I need to make sure I'm not gonna mess up or something like that (IL6, line 264).

Another woman described herself as "a zombie, like I'm half dead" (IL4, line 244), and admitted her fears about driving when she had not slept well. She further stated,

> If I want to drive somewhere, especially after lunch, I usually don't ever have caffeine ever, because I have osteoporosis, but I'll have to make myself a cup of instant coffee just so I can stay awake, because I'll be at a stop sign and my eyes will just close (IL4, line 175).

A third participant said her insomnia left her feeling "wobbly" and said it affected her cognitive function.

> Yeah. I definitely think that it makes me feel not quite in control. And that's a bad feeling for me. I'm a control freak to a large extent. And then, of course, as I've said, I feel slowed down and not quite as astute as I need to be (IL12, 184)

Others worried about how they would manage the following day, if they didn't get enough sleep the night before.

> If I have something I have to do, I want to be sure that I've got some sleep. I'm getting shots in my knee starting next week and so I've got to get to the doctor's office at 11:00. That means we gotta leave about 10:00 to fight the traffic to go downtown and that will worry me (IL10, line 182).

One woman described the contrast in her functioning when she had managed to sleep well [a good night].

> Oh, my day goes much better. When I have a good night sleep, I can do a lot. I've been getting up and making cookies for my friends and take them to supper and going to see the people over in healthcare that I know and doing things like that that I know – yesterday, I had slept so well. And I went over to my healthcare center. And my neighbor was over there. And she needed her clothes washed and dried. I went to her apartment and got everything done and just was still going strong.

Increased isolation occurred when participants curtailed social activities because of their exhaustion or because of the perceived threat of having a Bad Night as a result. Three participants specifically mentioned that they did not go to the evening movies shown at the community once a week because they were confident they would not be able to sleep afterwards (IL6, line 596; IL4, line 278; IL5, line 228).

SUMMARY

The purpose of this chapter was to report the findings from this qualitative descriptive study of the perceived effects of insomnia on older adults' quality of life and daily functioning. The findings reported in this chapter were the result of a qualitative descriptive data analysis process consistent with the qualitative methods described by Saldaña (2013) Hsieh and Shannon.

(Hsieh & Shannon, 2005). Qualitative interview data were analyzed to determine a main theme, categories, and sub-categories and were supplemented by widely used self-report sleep and anxiety assessment surveys. Out of the 18 participant interviews, the overall theme was Insomnia Is Exhausting. The overall theme consisted of four categories: A Bad Night, Self-management, Stoicism, and Consequences.

Chapter 5: Summary, Conclusion and Recommendations

Insomnia is a significant health problem that has far-reaching negative effects on older adults' quality of life and physical and cognitive functioning. Previous research on insomnia in older adults has employed quantitative methods, based on self-report sleep questionnaires or on objective measures obtained by actigraphy or polysomnography to gather data about older adults' sleep experience. However, insomnia is an inherently subjective experience that can be difficult to quantify, particularly considering that it is frequently triggered or exacerbated by factors like bereavement, recent relocation, anxiety, institutionalization, polypharmacy or comorbidities that are not explicitly addressed in the instruments and surveys commonly used in sleep research. Therefore, this study employed a qualitative descriptive approach to elicit self-report and open narratives from older adults at two different points along the trajectory of dependence about their own sleep behaviors, their knowledge of good sleep hygiene, and their thoughts and beliefs about the relationships between sleep, daily functioning and quality of life in order to understand how insomnia affects this population.

This chapter provides a summary and discussion of the findings and the implications on nursing practice and education, research, and policy.

INSOMNIA IS EXHAUSTING

The overriding theme of insomnia is exhausting describes the effect insomnia has on daily functioning and quality of life for the older adults in this study. The participants reported that their insomnia exhausted them, not only because many of them were chronically sleep deprived but also because they devoted so much physical and mental energy towards managing, containing or working around their insomnia. They also found the strain of worrying about their insomnia to be mentally and emotionally exhausting. Using Lawton's four sectors of quality of life (Figure 8), described in Chapter 2, as an interpretive guide, the participants in this study had good quality of

life in their Objective Environment, because the community was extremely well appointed and offered many activities, and they generally reported that their Perceived Quality of Life was good. However, their insomnia and the continual efforts they made to manage it affected their Psychological Well-being and, at times, their Behavioral Competence.

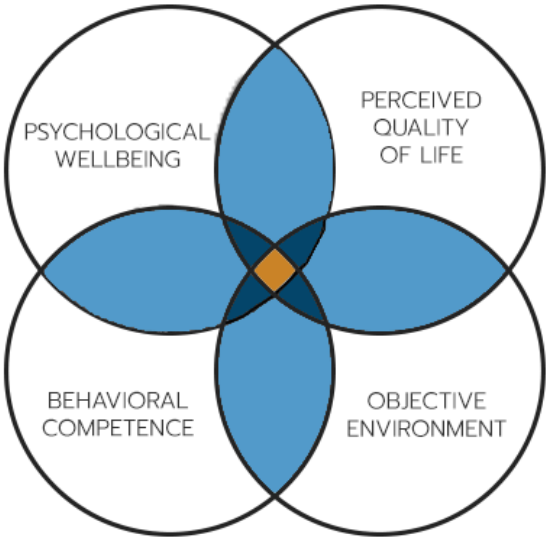


Figure 8. Four Sectors of Quality of Life.

Adapted from Lawton, M (1983). Environments and other determinants of well-being in older people. *The Gerontologist*, *23*(4), 349–357.

Living with chronic insomnia affected participants' Psychological Wellbeing by increasing their stress and anxiety, both about their own sleep and about other aspects of their lives. The unpredictability of insomnia made them at times fearful as they anticipated the lonely and frustrating prospect of being awake for hours in the night, and for many it became a constant risk factor that had to be worked around or reckoned with in their daily lives. Insomnia also affected their Behavioral Competence because they could not function well after being sleep deprived and

reported having to curtail activities that required clear thinking, like balancing a check book, because they felt they could not trust themselves when they were sleep deprived.

The experience of insomnia did appear to be different for participants residing at two different stages on the trajectory of dependence, but not because of any intrinsic differences in participants' sleep. The four participants from assisted living were noticeably more dependent than their neighbors in independent living, and all required assistance with activities of daily living. However, they were able to relate little of their increased dependence to their sleep experiences because all four were not in charge of their own bedtime schedules and were taking nightly medications that sedated them. Any effects their sleep may have had on their quality of life were outweighed by the effects of physical comorbidities or mental and emotional stresses they were experiencing from their increasing dependence. This overall theme of **"**Insomnia Is Exhausting" was described further by four categories: A Bad Night, Self-management, Stoicism, and Consequences.

A Bad Night

The category of A Bad Night described the experience of living with chronic insomnia. A Bad Night evoked emotional reactions of loneliness and anxiety as participants described lying alone and awake in the dark for hours. They spoke of frustration with racing thoughts that would not allow them to sleep and of anxiety about the sleeplessness itself. Under Lawton and Nahemow's Ecological Theory of Aging, A Bad Night represents a type of environmental press. The physical experience of A Bad Night regularly pushed participants away from their Zones of Maximum Comfort and Performance Potential towards Maladaptive Behaviors like self-isolation and depressed mood that threatened their quality of life. Anxiety over the possible prospect of A Bad Night also exerted environmental press and left participants frustrated over their lack of control.

In describing A Bad Night, many participants speculated about the precipitating factors that triggered their insomnia. According to Spielman, Caruso and Glovinsky, common

precipitating factors include life events and medical, environmental or psychological factors can trigger acute insomnia (Spielman et al., 1987). The older adults in this study declared their most common precipitating factors to be bereavement (IL7, IL10, IL18, IL20) retirement (IL3, IL8, IL12), moving to an institutional living situation (IL6, IL11, AL25) and the onset or worsening of a chronic illness (IL4, IL5, IL11, IL13, IL15). Each of these major life events would be enough to trigger acute insomnia in a healthy adult, but for many of these older adults the events are a reminder of their own frailty and potential loss of independence and autonomy. The research literature offers little comment on this category because there have been so few qualitative studies of the experience of insomnia in older adults.

Self-management

The second category of self-management describes many of the sleep hygiene practices, both successful and unsuccessful, that the independent living older adults employed. The most commonly used behaviors were exercising regularly, keeping to fixed sleep-wake schedules, and restricting caffeine intake late in the day, all of which are endorsed in moderation by the National Sleep Foundation. However, none of these practices were enough to significantly improve any single participant's sleep, because the only two participants who claimed to have "cured" their insomnia attributed their improved sleep to medication. Under the Ecological Theory of Aging, these self-management practices can be viewed as attempts by participants to exercise their personal competences to counter the exhausting effects of insomnia and move closer to their ideal Adaptation Level. However, in most cases the practices were applied haphazardly, or were espoused as an ideal that was hard to apply in practice. For example, some participants restricted their caffeine intake, while others used coffee as a stimulant to compensate for their exhaustion, even though they knew they were likely to have to deal with its stimulant effects later.

Woodley and Smith (2006) explored the intersection of dysfunctional beliefs about sleep with what they termed "sleep-specific safety behaviors," that is, behaviors that act to maintain and perpetuate insomnia by reinforcing pre-existing dysfunctional beliefs about sleep (Woodley &

Smith, 2006). The researchers took the concept from Harvey's cognitive model of insomnia, which was based around treatments for anxiety. Safety behaviors are defined as behaviors that are adopted to avoid a feared situation, and Harvey and Woodley and Smith and others have proposed that sleep-related safety behaviors are used at night due to the fear of disturbed sleep, or during the day as coping mechanisms following a night of disturbed sleep (Harvey, 2002; Woodley & Smith, 2006). None of the study participants who employed self-management behaviors for insomnia had done so on the specific advice of a therapist or healthcare provider; rather they had cobbled together beliefs and practices from internet articles and their own experience, and most admitted that their efforts were only occasionally successful at best. It seems that many of these attempts at self-management would qualify as sleep-related safety behaviors and that participants could benefit from professional guidance in insomnia treatment. Current best-practice guidelines include keeping to a regular sleep and wake routine, even at weekends; avoiding caffeine and alcohol at least three hours before bedtime; creating a bedtime relaxing routine that avoids screen exposure; and using the bed and bedroom only for sleep and sex (Hirshkowitz et al., 2015; Sateia et al., 2017; Stepanski & Wyatt, 2003; Zeitzer, Friedman, & Yesavage, 2011).

None of the participants mentioned any other possible therapies besides medication. Even the few who had consulted a sleep specialist or received a sleep study (Polysomnogram) did not mention any alternatives to medications, such as cognitive behavioral therapy, or yoga, tai chi, or mindfulness meditation, for example. As noted in Chapter 2, a number of intervention studies have been conducted that aimed to improve older adults' sleep quality through therapies such as yoga, tai chi, mindfulness, or exercise (Black, O'Reillby, Olmstead, Breen, & Irwin, 2015; Chan et al., 2016; Lai et al., 2017; Sivakumar et al., 2013), and each of these interventions was successful at improving scores on the PSQI and different quantitative quality of life scales. But when asked what insomnia treatments they had tried or been recommended, none of the participants mentioned any of these behavioral therapies.

Stoicism

The third category of Stoicism, of carrying on and not giving into to the exhaustion of their insomnia, was closely linked to participants' efforts at self-management, and could also be considered a sleep-related safety behavior. However, Stoicism also seemed to be connected to their values, beliefs and behaviors about aging. Participants talked about their health problems or recent surgeries with much of the same vocabulary they used to describe their insomnia; as something they had to manage and navigate. The stoic attitudes about insomnia and adherence to exercise regimes and schedules seemed to be part of a larger ethic about carrying on in the face of adversity.

Another characteristic of this stoicism about their insomnia had to do with keeping up appearances. Living in a retirement community surrounded by other older adults meant that everyone is confronting failing health and the prospect of disability. So for many, it was important to continue to socialize, attend the water aerobics classes and play bridge so that your neighbors knew you were still alive and well.

But the stigma many participants assigned to napping appeared to be especially counter-productive. People who have had a poor night's sleep often nap the next day as compensation. The power nap is increasingly encouraged among business people and naps of 30-45 minutes are recommended for college students before exams. The National Sleep Foundation's Sleep.org website promotes a 20-minute nap as "a natural way to revive your energy" because it is not so long that it makes you groggy or unable to sleep at night (National Sleep Foundation, 2019). It is curious, therefore that these participants, who were fairly well informed about many other aspects of sleep, were so adamantly opposed to napping.

Research has shown some correlations between older adults' napping habits and increased medical comorbidities and risks of dementia, but it has also shown that napping enhances memory consolidation and broader aspects of cognition in younger adults. Where along the aging spectrum this line between beneficial napping and potentially risky napping falls is not clear. Cross et al (2015) acknowledged this issue in their study of napping habits in 133 older adults 'at risk' of dementia. Using both actigraphy and self-report assessment, they found that nappers had greater

medical burden, body mass index and poorer cognitive function (Cross et al., 2015). However, they noted that there is a need to examine the benefits of planned and controlled napping, as opposed to merely analyzing retrospectively the correlates of uncontrolled and unplanned napping, especially among a group of older adults with multiple comorbidities. Their conclusions were encouraging:

> Planned and controlled napping may be a feasible and cost-effective method for improving declarative (e.g., episodic or semantic) memory in people with a disorder of memory consolidation, and specifically in those with amnestic MCI [mild cognitive impairment] (Cross et al., 2015).

While research about the relationships between disordered sleep and cognitive impairment is still at an early stage, it seems ironic that the participants in this study stigmatized planned napping, which could potentially benefit their cognitive functioning, but seemed accepting of accidental napping, which may well indicate some more serious cognitive issues. More education about sleep needs for older adults is needed.

Consequences

Most participants were able to describe the immediate effects a night of short sleep, or sleep deprivation had on their physical and cognitive functioning. They felt exhausted, unmotivated, lethargic, and frequently angry and frustrated. They also described, sometimes indirectly, the effects that chronic insomnia as a condition had on their quality of life over time. These effects included increased stress and anxiety as they worried about their sleep loss and some dreaded going to bed. The effects also included increased isolation and reduced autonomy because some participants reduced their social interactions, worried about their ability to drive and felt less confident in themselves. Some feared the effects of sleep medication or the possible interactions of sleep medications with other drugs, more than they feared their insomnia. Chronic insomnia made most of the participants feel that they were not in control of their lives and the sometimes random or haphazard ways they tried to deal with this problem often perpetuated it.

In the only other qualitative study of insomnia found so far, Kemple, O'Toole, and O'Toole (2016) examined the experience of insomnia in nine community-living Irish adults with chronic illnesses. Their study of seven men and two women with multiple chronic illnesses including heart failure, rheumatoid arthritis, and coronary heart disease revealed two contradictory themes: participants reported that they knew "something was wrong" but also denied the problem, "I am fine" (Kemple, O'Toole, & O'Toole, 2016). Like their Texan counterparts, the Irish participants also indicated that "they knew napping was not good…but also did not manage to identify how they might prevent this from occurring" (Kemple et al., 2016, p. 3368). More research into the real risks or benefits of napping would be helpful to people with insomnia at many stages of life.

LIMITATIONS

There were several limitations in this study. The participants were residents at an upscale retirement community in Central Texas and caution should be employed in comparing the results of this study to other groups of adults, either living in less affluent retirement communities or in their own homes. In addition, the participants were all non-Hispanic whites and do not represent the breadth of experience or perspectives of a more racially and ethnically diverse sample. Third, the interviews and the survey results relied on self-report data and experiences and may be subject to recall bias. Finally, the interviewer did not have access to participants' medical records to verify any of their statements, but the intention of this study was to describe the participant experience.

IMPLICATIONS FOR NURSING EDUCATION AND PRACTICE

Nursing practice would benefit from a greater awareness of the importance of sleep to all sectors of the population. Many nursing textbooks address sleep only in the context of certain diseases (Alzheimer's disease, cancer). But the issue is especially important when nursing older adults. Too often ageist stereotypes about sleep habits blind healthcare providers to real issues in physical and mental health and lead to unnecessary suffering. When assessing sleep in older adults, nurses must not simply ask "how are you sleeping?" but probe further to determine sleep

duration, number of awakenings, napping habits, and how patients feel about their sleep. Older adults too, may have accepted the stereotype that poor sleep comes with age and not tell their healthcare provider because it is not as big a problem as their cardiovascular disease, diabetes or arthritis. Healthcare providers need to be aware that sleep affects the whole person and can have as much impact on the trajectory and management of their chronic disease as the proper medications or treatment.

IMPLICATIONS FOR RESEARCH

The findings from this study offer insight for researchers wanting to improve sleep for older adults. There is a serious lack of research regarding insomnia in older adults and this study is an initial step in filling this knowledge gap. Sleep assessment tools like the PSQI and the ISI do not sufficiently capture aspects of older adults' sleep experience. The instruments should be modified to reflect the latest definitions and diagnostic criteria for insomnia from the DSM-5. But more specifically, the format and time periods encompassed by the instruments are not precise enough for older adults with severe sleep problems. For example, on Item 5b, the PSQI cannot differentiate between someone who wakes once per night to go to the bathroom several nights a week (score 3) and someone who wakes four times a night every night (also score 3) although the latter is clearly a much more disruptive problem. Similarly, the Sleep Hygiene Index asks about daytime napping but only "more than 2 hours" which is unhelpful, when the National Sleep Foundation warns against napping more than 90 minutes. An older adult who naps for an hour every day late in the afternoon might be unknowingly affecting his or her sleep, but that habit would not be caught under the most commonly used sleep hygiene assessment.

This study revealed many issues that need to be addressed to help older adults sleep better and to better understand the effects of insomnia on older adults' daily functioning and quality of life. The following questions are particularly relevant:

- How do older adults' subjective perceptions of their sleep compare with objective measurements (using actigraphy)?

- What is the effect of polypharmacy on older adults' sleep and the use of melatonin and/or antidepressants?
- How might the results of this study vary with a sample of older adults living in the community? How might the results vary in a low-income senior community?
- What is the effect of insomnia on quality of life for people with dementia, that is, moving another step down the trajectory of dependence? The voices of people with dementia need to be included in research about the links between insomnia and cognitive impairment.

IMPLICATIONS FOR POLICY

The importance of good sleep has been highlighted by the U.S. government in its Healthy People 2020 public health initiatives. Specifically, the goal is to increase public knowledge of how adequate sleep and treatment of sleep disorders improve health, productivity, wellness, quality of life, and safety on roads and in the workplace (US Department of Health and Human Services, 2010). These objectives have huge impact for organizations that run senior living communities and long-term care facilities. Many studies have shown that residents of long-term care facilities experience poor sleep due to noisy environments, inconsiderate care practices (like checking vital signs at 5:30am) and the lack of individualized care plans (Bankar, Chaudhari, & Chaudhari, 2013; Martin & Ancoli-Israel, 2008; Voyer et al., 2006). In addition, the Omnibus Budgeting Reconciliation Act of 1987, also called the Nursing Home Reform Act, and the 1987 amendments to the Older Americans Act, provided for reform in the areas of nurse's aide training, among several other reforms, but did not specify curricula for Certified Nurse Aide (CNA) training, which is determined at the state level (Office of the Inspector General, 2002). Sleep hygiene and the importance of good sleep to older adults' quality of life and daily functioning should be included in all CNA training across the country. Even at comparatively higher levels on the trajectory of dependence, like assisted living, residents can easily lose autonomy and the potential to maintain their own natural sleep patterns. Administrators and directors of nursing should exercise caution with assumptions about the abilities of people at different levels of the trajectory and offer as much

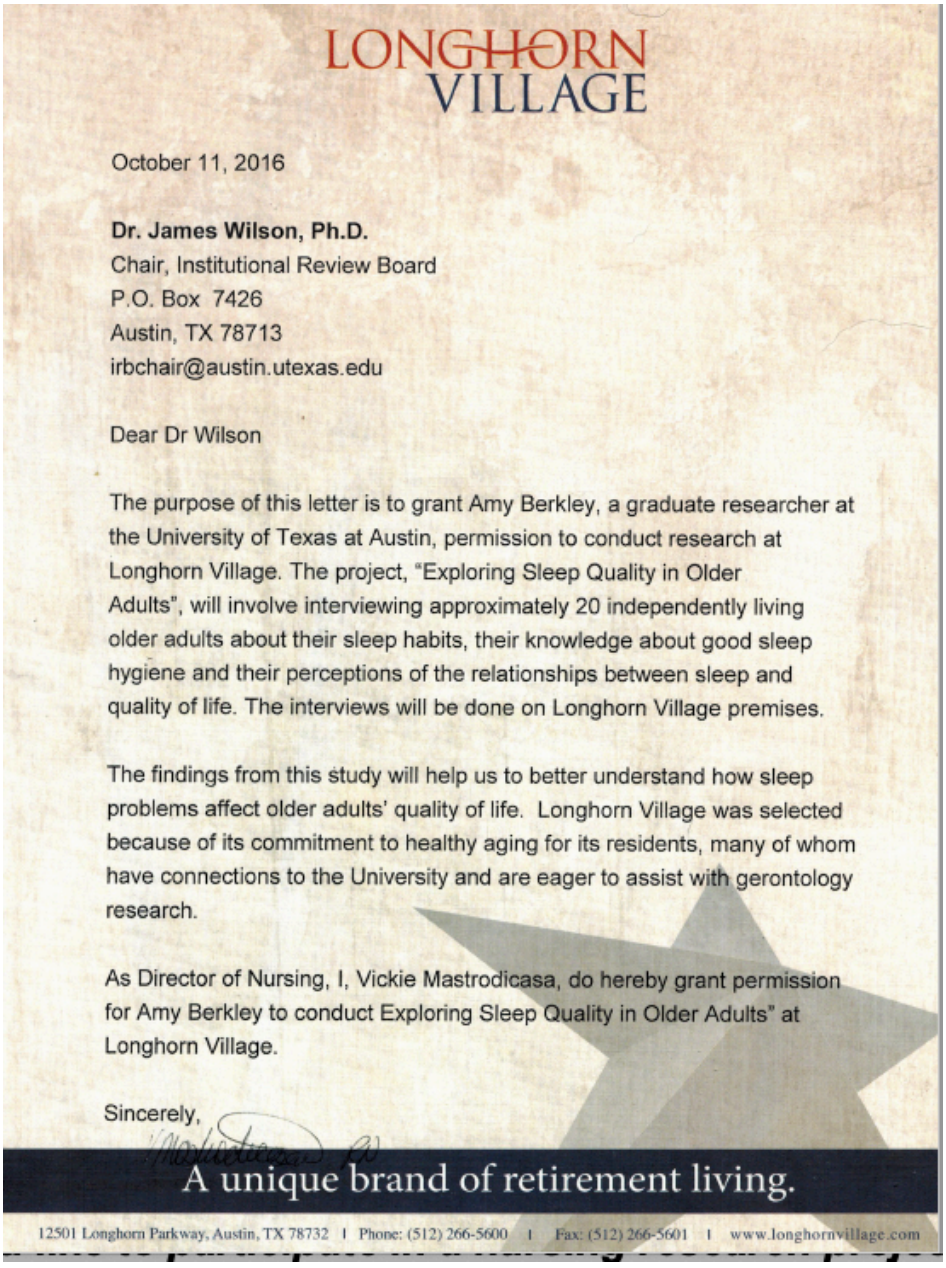
autonomy as they can. But they should also work to ensure that their employees are well trained in the importance of sleep for older adults.

CONCLUSION

This chapter provided a summary of the findings from this study and a discussion of their significance and their implications for nursing practice and education, research and policy. By employing qualitative methods that captured a more holistic and nuanced experience of insomnia, this study demonstrated the negative effects that insomnia has on older adults' quality of life and daily functioning. Conventional content analysis of the participants' narratives revealed the overriding theme of Insomnia Is Exhausting, which exemplifies the physical and emotional strain this chronic condition creates. Using the terms of Lawton and Nahemow's Ecological Theory of Aging, insomnia and its consequences are sources of environmental press that push older adults away from their Zones of Maximum Comfort and Performance and impair their daily functioning. This study has significant implications for nursing practice and education, research and policy.

Appendices

Appendix A – Site Approval Letter



LONGHORN VILLAGE

October 11, 2016

Dr. James Wilson, Ph.D.
Chair, Institutional Review Board
P.O. Box 7426
Austin, TX 78713
irbchair@austin.utexas.edu

Dear Dr Wilson

The purpose of this letter is to grant Amy Berkley, a graduate researcher at the University of Texas at Austin, permission to conduct research at Longhorn Village. The project, "Exploring Sleep Quality in Older Adults", will involve interviewing approximately 20 independently living older adults about their sleep habits, their knowledge about good sleep hygiene and their perceptions of the relationships between sleep and quality of life. The interviews will be done on Longhorn Village premises.

The findings from this study will help us to better understand how sleep problems affect older adults' quality of life. Longhorn Village was selected because of its commitment to healthy aging for its residents, many of whom have connections to the University and are eager to assist with gerontology research.

As Director of Nursing, I, Vickie Mastrodicasa, do hereby grant permission for Amy Berkley to conduct Exploring Sleep Quality in Older Adults" at Longhorn Village.

Sincerely,

A unique brand of retirement living.

12501 Longhorn Parkway, Austin, TX 78732 | Phone: (512) 266-5600 | Fax: (512) 266-5601 | www.longhornvillage.com

APPENDIX B – IRB ACCEPTANCE

2016-07-0074 Exempt Amendment Application - Acknowledged

Hammock, Meghan A mhammock@austin.utexas.edu via utexas.onmicrosoft.com Fri, Feb 22, 7:23 AM
to Patricia, me

RE: Exploring Sleep Quality in Older Adults

Dear Patricia A Carter,

Thank you for notifying our office of the changes to the above-listed protocol. The proposed changes to the protocol have been acknowledged as not increasing the risk toward study participants. The protocol may continue under an Exempt determination status.

A copy of this communication will be maintained in the study file. The amendment application status will show withdrawn.

Note: Amendments to Exempt level studies are ONLY required in the following circumstances:

- Change in Principal Investigator
- Changes to study procedures or documents that increase risk
- Changes to study procedures such that the research will no longer qualify for an Exemption

If you are unsure whether a proposed change must be submitted as an amendment, please contact the ORSC for guidance prior to submitting.

Thank you,

Meghan Hammock
Senior IRB Analyst
Office of Research Support & Compliance
Phone: 512-232-2625
Fax: 512-471-2827
Coordinator Hours: Monday- Friday 7:00 a.m. – 4:00 p.m. CST

Sharpen your horns and stay in the know with our IRB newsletter!

APPENDIX C – RECRUITMENT LEAFLET

THE UNIVERSITY OF TEXAS AT AUSTIN

WHAT STARTS HERE CHANGES THE WORLD

Do you sometimes have trouble sleeping?
Are you interested in learning how you can sleep better?
Would you like to participate in a nursing research project?

Call for Volunteers

Residents of Longhorn Village are invited to participate in a research study entitled "The Effects of Insomnia on Older Adults' Quality of Life". The purpose of this study is to discover how sleep disorders like insomnia affect people's daily functioning, and to explore the thoughts and beliefs people have about good sleep.

This study is being conducted by Texas Exes/ Longhorn Village Gerontology Nursing Scholar, Amy Berkley, RN, for her PhD dissertation, under the direction of her advisor, Dr. Patricia Carter, at the School of Nursing at the University of Texas at Austin.

Participating would involve completing 5 questionnaires about sleep habits, anxiety, and living environment; filling out a daily "sleep diary" for 7 days; then having a brief (20-min) interview with Amy about how you cope with insomnia and how your sleep affects your daily life. There is also an option to wear a motion-sensing, sleep tracking wristwatch for 7 days.

If you are over age 65, and living independently or in assisted living, and would like to participate, please contact Amy at (512) 850-3212, or email her directly at: amysberkley@utexas.edu

APPENDIX D – INFORMATIONAL LETTER

Informational Letter for Research Study

Identification of Investigator and Purpose of Study

You are invited to participate in a research study, entitled "Exploring sleep quality in older adults". The study is being conducted by Amy Berkley, RN, PhD candidate and Dr. Pat Carter, associate professor of nursing of The University of Texas at Austin, 1710 Red River, Austin TX. 78701, (512) 850-3212, amysberkley@utexas.edu

The purpose of this research study is to examine the relationship between insomnia or disrupted sleep and functional ability in older adults. Your participation in the study will contribute to a better understanding of the role sleep plays in the daily lives of persons over the age of 65 years. You are free to contact the investigator at the above address and phone number to discuss the study. You must be at least 65 years old to participate.

If you agree to participate:

- The questionnaires and interview will take approximately 45-60 minutes of your time in total over two meetings. The sleep diary will take about 3-4 minutes to complete each day for 7 days.
- At our first meeting you will complete questionnaires about your sleep habits (2), knowledge of sleep hygiene, beliefs about sleep, and anxiety level. It will take about 20-25 minutes to complete the questionnaires.
- After the questionnaires, you will be asked to take home a sleep diary and complete it each morning for 7 days.
- A week or so later you will participate in a one-on-one, audio-recorded interview to express your thoughts and beliefs about the roles that sleep plays in your everyday life (will take 30-45 minutes to complete). There will be a short (3-question) cognitive test after the interview.
- If you decide to participate in the optional sleep actigraphy activity, you will wear a wrist
- You will not be compensated for your participation in this study.

Risks/Benefits/Confidentiality of Data

There are no known risks to you participating**.** There will be no costs for participating, nor will you benefit from participating. Your name and email address will be kept during the data collection phase for tracking purposes only. A limited number of research team members will have access to the data during data collection. Identifying information will be stripped from the final dataset.

Participation or Withdrawal

Your participation in this study is voluntary. You may decline to answer any question and you have the right to withdraw from participation at any time. Withdrawal will not affect your relationship with The University of Texas in anyway. If you do not want to participate either simply stop participating or inform the interviewer that you wish to stop.

Contacts
If you have any questions about the study or need to update your email address contact the researcher Amy Berkley at (512) 850-3212 or send an email to amysberkley@utexas.edu**.** This study has been reviewed by The University of Texas at Austin Institutional Review Board and the study number is **2016-07-0074.**

Questions about your rights as a research participant.
If you have questions about your rights or are dissatisfied at any time with any part of this study, you can contact, anonymously if you wish, the Institutional Review Board by phone at (512) 471-8871 or email at orsc@uts.cc.utexas.edu.

Thank you.

Please keep this document for your records.

APPENDIX E – DEMOGRAPHIC FORM

Today's Date _____ Participant # _____

1	**Date of birth? _____**	**Age? _____**
2	**Gender (please circle) ---->**	**Male Female**
3	**Marital status (please circle) ---->**	**Single Married** **Partnered Widowed**
4	**Ethnicity (please circle) ---->**	**Caucasian/Non-Hispanic White** **Hispanic** **African-American** **Asian** **Native American/Indian** **Other** **_____**
5	**Level of education ---->**	**High school**

	(please circle highest level completed)	Some college Associate degree Baccalaureate degree Graduate/post-graduate
6	Living situation (please circle) ----->	Independent Assisted
7	Approximately how long have you been in this living situation? ------->	_____ months? _____ years?
8	Do you have any of the following in the room where you sleep? ---------->	Bed partner (person) YES NO Pets YES NO Noisy equipment YES NO

APPENDIX F – THE PITTSBURGH SLEEP QUALITY INDEX

The Pittsburgh Sleep Quality Index (PSQI)

Instructions: The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions. During the past month,

1. When have you usually gone to bed? _____
2. How long (in minutes) has it taken you to fall asleep each night? _____
3. When have you usually gotten up in the morning? _____
4. How many hours of actual sleep do you get at night? (This may be different than the number of hours you spend in bed) _____

5. During the past month, how often have you had trouble sleeping because you…	Not during the past month (0)	Less than once a week (1)	Once or twice a week (2)	Three or more times week (3)
a. Cannot get to sleep within 30 minutes				
b. Wake up in the middle of the night or early morning				
c. Have to get up to use the bathroom				
d. Cannot breathe comfortably				
e. Cough or snore loudly				
f. Feel too cold				
g. Feel too hot				
h. Have bad dreams				
i. Have pain				
j. Other reason(s), please describe, including how often you have had trouble sleeping because of this reason(s):				
6. During the past month, how often have you taken medicine (prescribed or "over the counter") to help you sleep?				
7. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?				
8. During the past month, how much of a problem has it been for you to keep up enthusiasm to get things done?				
	Very good (0)	Fairly good (1)	Fairly bad (2)	Very bad (3)
9. During the past month, how would you rate your sleep quality overall?				

APPENDIX G – THE SLEEP HYGIENE INDEX

SLEEP HYGIENE INDEX (SHI)

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale to make your choice.

0	1	2	3	4
Never	Rarely	sometimes	Frequent	Always

1. I take daytime naps lasting two or more hours.	0 1 2 3 4	_____
2. I go to bed at different times from day to day.	0 1 2 3 4	_____
3. I get out of bed at different times from day to day.	0 1 2 3 4	_____
4. I exercise to the point of sweating within 1 hr of going to bed.	0 1 2 3 4	_____
5. I stay in bed longer than I should two or three times a week.	0 1 2 3 4	_____
6. I use alcohol, tobacco, or caffeine within 4hrs of going to bed or after going to bed.	0 1 2 3 4	_____
7. I do something that may wake me up before bedtime (for example: play video games, use the internet, or clean).	0 1 2 3 4	_____
8. I go to bed feeling stressed, angry, upset, or nervous.	0 1 2 3 4	_____
9. I use my bed for things other than sleeping or sex (for example: watch television, read, eat, or study).	0 1 2 3 4	_____
10. I sleep on an uncomfortable bed (for example: poor mattress or pillow, too much or not enough blankets).	0 1 2 3 4	_____
11. I sleep in an uncomfortable bedroom (for example: too bright, too stuffy, too hot, too cold, or too noisy).	0 1 2 3 4	_____
12. I do important work before bedtime (for example: pay bills, schedule, or study).	0 1 2 3 4	_____
13. I think, plan, or worry when I am in bed.	0 1 2 3 4	_____
	Total score =_____	

APPENDIX H – THE INSOMNIA SEVERITY INDEX

Insomnia Severity Index

The Insomnia Severity Index has seven questions. The seven answers are added up to get a total score. When you have your total score, look at the 'Guidelines for Scoring/Interpretation' below to see where your sleep difficulty fits.

For each question, please CIRCLE the number that best describes your answer.

Please rate the CURRENT (i.e. LAST 2 WEEKS) SEVERITY of your insomnia problem(s).

Insomnia Problem	None	Mild	Moderate	Severe	Very Severe
1. Difficulty falling asleep	0	1	2	3	4
2. Difficulty staying asleep	0	1	2	3	4
3. Problems waking up too early	0	1	2	3	4

4. How SATISFIED/DISSATISFIED are you with your CURRENT sleep pattern?

Very Satisfied	Satisfied	Moderately Satisfied	Dissatisfied	Very Dissatisfied
0	1	2	3	4

5. How NOTICEABLE to others do you think your sleep problem is in terms of impairing the quality of your life?

Not at all Noticeable	A Little	Somewhat	Much	Very Much Noticeable
0	1	2	3	4

6. How WORRIED/DISTRESSED are you about your current sleep problem?

Not at all Worried	A Little	Somewhat	Much	Very Much Worried
0	1	2	3	4

7. To what extent do you consider your sleep problem to INTERFERE with your daily functioning (e.g. daytime fatigue, mood, ability to function at work/daily chores, concentration, memory, mood, etc.) CURRENTLY?

Not at all Interfering	A Little	Somewhat	Much	Very Much Interfering
0	1	2	3	4

Guidelines for Scoring/Interpretation:

Add the scores for all seven items (questions 1 + 2 + 3 + 4 + 5 +6 + 7) = _____ your total score

Total score categories:
0–7 = No clinically significant insomnia
8–14 = Subthreshold insomnia
15–21 = Clinical insomnia (moderate severity)
22–28 = Clinical insomnia (severe)

Used via courtesy of www.myhealth.va.gov with permission from Charles M. Morin, Ph.D., Université Laval

APPENDIX I - THE GERIATRIC ANXIETY SCALE

Geriatric Anxiety Scale – 10 Item Version (GAS-10)

Below is a list of common symptoms of anxiety or stress. Please read each item in the list carefully. Indicate how often you have experienced each symptom during the PAST WEEK, INCLUDING TODAY by checking under the corresponding answer.

	Not at all (0)	Sometimes (1)	Most of the time (2)	All of the time (3)
1. I was irritable.				
2. I felt detached or isolated from others.				
3. I felt like I was in a daze.				
4. I had a hard time sitting still.				
5. I could not control my worry.				
6. I felt restless, keyed up, or on edge.				
7. I felt tired.				
8. My muscles were tense.				
9. I felt like I had no control over my life.				
10. I felt like something terrible was going to happen to me.				

Beliefs About Sleep

Several statements reflecting people's beliefs and attitudes about sleep are listed below. Please indicate (by circling the number) to what extent you personally agree or disagree with each statement.

There is no right or wrong answer. ***For each statement, circle a number that best reflects your personal experience.*** Consider the whole scale, rather than only the extremes of the continuum.

1. I need 8 hours of sleep to feel refreshed and function well during the day.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree									Strongly Agree

2. When I do not get proper amount of sleep on a given night, I need to catch up on the next day by napping or on the next night by sleeping longer.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree									Strongly Agree

3. I am concerned that chronic insomnia may have serious consequences for my physical health.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree									Strongly Agree

4. I am worried that I may lose control over my abilities to sleep.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree									Strongly Agree

5. After a poor night's sleep, I know that it will interfere with my daily activities on the next day.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree									Strongly Agree

6. In order to be alert and function well during the day, I am better off taking a sleep pill rather than having a poor night's sleep.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree									Strongly Agree

7. When I feel irritable, depressed, or anxious during the day, it is mostly because I did not sleep well the night before.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree								Strongly Agree	

8. When I sleep poorly on one night, I know that it will disturb my sleep schedule for the whole week.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree								Strongly Agree	

9. Without an adequate night's sleep, I can hardly function the next day.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree								Strongly Agree	

10. I can't ever predict whether I will have a good or poor night's sleep.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree								Strongly Agree	

11. I have little ability to manage the negative consequences of disturbed sleep.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree								Strongly Agree	

12. When I feel tired, have no energy, or just seem not to function well during the day, it is generally because I did not sleep well the night before.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree								Strongly Agree	

13. I believe that insomnia is generally a result of a chemical imbalance.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree								Strongly Agree	

14. I feel that insomnia is ruining my ability to enjoy life and prevents me from doing what I want.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree								Strongly Agree	

15. Medication is probably the only solution to sleeplessness.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree								Strongly Agree	

16. I avoid or cancel obligations (social, family, occupational) after a poor night's sleep.

1	2	3	4	5	6	7	8	9	10
Strongly Disagree								Strongly Agree	

Morin, C., Vallières, A., Ivers, H. (2007). Dysfunctional beliefs and attitudes about sleep (DBAS): Validation of a brief version (DBAS-16). *SLEEP*, 30(11):1547-1554

APPENDIX K – THE CONSENSUS SLEEP DIARY

Consensus Sleep Diary-M (Please Complete Upon Awakening) **ID/NAME:** _____

	Sample							
Today's Date	4/5/08							
1. What time did you get into bed?	10:15 p.m.							
2. What time did you try to go to sleep?	11:30 p.m.							
3. How long did it take you to fall asleep?	55 min.							
4. How many times did you wake up, not counting your final awakening?	6 times							
5. In total, how long did these awakenings last?	2 hours 5 min.							
6a. What time was your final awakening?	6:35 a.m.							
6b. After your final awakening, how long did you spend in bed trying to sleep?	45 min.							
6c. Did you wake up earlier than you planned?	☑ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
6d. If yes, how much earlier?	1 hour							
7. What time did you get out of bed for the day?	7:20 a.m.							
8. In total, how long did you sleep?	4 hours 10 min.							
9. How would you rate the quality of your sleep?	☐ Very poor ☑ Poor ☐ Fair ☐ Good ☐ Very good	☐ Very poor ☐ Poor ☐ Fair ☐ Good ☐ Very good	☐ Very poor ☐ Poor ☐ Fair ☐ Good ☐ Very good	☐ Very poor ☐ Poor ☐ Fair ☐ Good ☐ Very good	☐ Very poor ☐ Poor ☐ Fair ☐ Good ☐ Very good	☐ Very poor ☐ Poor ☐ Fair ☐ Good ☐ Very good	☐ Very poor ☐ Poor ☐ Fair ☐ Good ☐ Very good	☐ Very poor ☐ Poor ☐ Fair ☐ Good ☐ Very good
10. How rested or refreshed did you feel when you woke-up for the day?	☐ Not at all rested ☑ Slightly rested ☐ Somewhat rested ☐ Well-rested ☐ Very well-rested	☐ Not at all rested ☐ Slightly rested ☐ Somewhat rested ☐ Well-rested ☐ Very well-rested	☐ Not at all rested ☐ Slightly rested ☐ Somewhat rested ☐ Well-rested ☐ Very well-rested	☐ Not at all rested ☐ Slightly rested ☐ Somewhat rested ☐ Well-rested ☐ Very well-rested	☐ Not at all rested ☐ Slightly rested ☐ Somewhat rested ☐ Well-rested ☐ Very well-rested	☐ Not at all rested ☐ Slightly rested ☐ Somewhat rested ☐ Well-rested ☐ Very well-rested	☐ Not at all rested ☐ Slightly rested ☐ Somewhat rested ☐ Well-rested ☐ Very well-rested	☐ Not at all rested ☐ Slightly rested ☐ Somewhat rested ☐ Well-rested ☐ Very well-rested

Consensus Sleep Diary-M Continued **ID/NAME:** _____

	Sample							
Today's Date	4/5/10							
11a. How many times did you nap or doze? 11b. In total, how long did you nap or doze?	2 times 1 hour 10 min.							
12a. How many drinks containing alcohol did you have? 12b. What time was your last drink?	3 drinks 9 :20 p.m.							
13a. How many caffeinated drinks (coffee, tea, soda, energy drinks) did you have? 13b. What time was your last drink?	2 drinks 3 :00 p.m.							
14. Did you take any over-the-counter or prescription medication(s) to help you sleep? If so, list medication(s), dose, and time taken	☑ Yes ☐ No Medication(s): Relaxo-Herb Dose: 50 mg Time(s) taken: 11 pm	☐Yes ☐No Medication(s): Dose: Time(s) taken:	☐Yes ☐No Medication(s): Dose: Time(s) taken:	☐Yes ☐No Medication(s): Dose: Time(s) taken:	☐Yes ☐No Medication(s): Dose: Time(s) taken:	☐Yes ☐No Medication(s): Dose: Time(s) taken:	☐Yes ☐No Medication(s): Dose: Time(s) taken:	☐Yes ☐No Medication(s): Dose: Time(s) taken:
15. Comments (if applicable)	I have a cold							

APPENDIX L – THE MINI-COG

Mini-Cog©

Instructions for Administration & Scoring

ID:_____ Date: _____

Step 1: Three Word Registration

Look directly at person and say, "Please listen carefully. I am going to say three words that I want you to repeat back to me now and try to remember. The words are [select a list of words from the versions below]. Please say them for me now." If the person is unable to repeat the words after three attempts, move on to Step 2 (clock drawing).

The following and other word lists have been used in one or more clinical studies.[1-3] For repeated administrations, use of an alternative word list is recommended.

Version 1	Version 2	Version 3	Version 4	Version 5	Version 6
Banana	Leader	Village	River	Captain	Daughter
Sunrise	Season	Kitchen	Nation	Garden	Heaven
Chair	Table	Baby	Finger	Picture	Mountain

Step 2: Clock Drawing

Say: "Next, I want you to draw a clock for me. First, put in all of the numbers where they go." When that is completed, say: "Now, set the hands to 10 past 11."

Use preprinted circle (see next page) for this exercise. Repeat instructions as needed as this is not a memory test. Move to Step 3 if the clock is not complete within three minutes.

Step 3: Three Word Recall

Ask the person to recall the three words you stated in Step 1. Say: "What were the three words I asked you to remember?" Record the word list version number and the person's answers below.

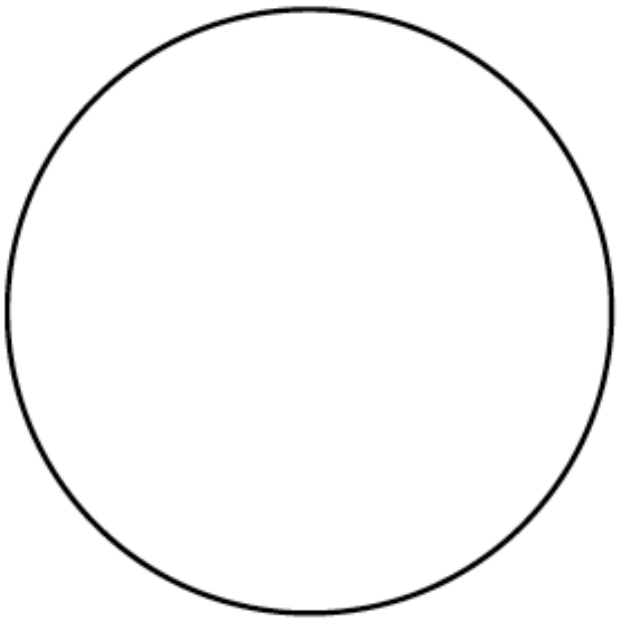
Word List Version:_____ Person's Answers: _____ _____ _____

Scoring

Word Recall: _____ (0-3 points)	1 point for each word spontaneously recalled without cueing.
Clock Draw: _____ (0 or 2 points)	Normal clock = 2 points. A normal clock has all numbers placed in the correct sequence and approximately correct position (e.g., 12, 3, 6 and 9 are in anchor positions) with no missing or duplicate numbers. Hands are pointing to the 11 and 2 (11:10). Hand length is not scored. Inability or refusal to draw a clock (abnormal) = 0 points.
Total Score: _____ (0-5 points)	Total score = Word Recall score + Clock Draw score. A cut point of <3 on the Mini-Cog™ has been validated for dementia screening, but many individuals with clinically meaningful cognitive impairment will score higher. When greater sensitivity is desired, a cut point of <4 is recommended as it may indicate a need for further evaluation of cognitive status.

Clock Drawing

ID:_____ Date:_____



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APPENDIX M– SEMI-STRUCTURED INTERVIEW QUESTIONS

The face-to-face interviews were based around open-ended questions to encourage participants to describe their thoughts and beliefs about sleep and sleep's impact on daily functioning. Sample questions (listed below) were expanded with follow-up prompts (e.g. tell me more, can you give me an example).

- Please describe how your sleep has changed over the years.
- We are interested in knowing more about what people believe and think about the role sleep plays in their life.
    - Will you please tell us about what your day is like after a good night's sleep?
    - Will you please tell us about what your day is like after a poor (bad) night's sleep?
    - How do you think that sleep influences your daily functioning, if at all?
- Is there anything else you would like to share about how sleep quality impacts your life?

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